



Individual Healthcare Plan (IHP) England, Wales, Scotland / **Individual Education Plan (IEP)** Northern Ireland

For any child or young person with arthritis or
being seen by the rheumatology team

FOR USE IN NURSERY, SCHOOL, COLLEGE OR ANY EDUCATION SETTING

Individual Healthcare Plan/ Individual Education Plan (IHP/ IEP)

Step-by-Step Guide



1

Ask the education provider for a meeting.



4

Read the guidance notes and consider which ones are relevant for your child or young person.

2

Download this IHP/ IEP form.



5

Attend the meeting with the education provider and complete the IHP/ IEP together, filling in actions and responsibilities and the Individual Impact Statement.



Use the guidance notes to guide the conversation.

3

Send the IHP/ IEP forms link to the education provider so that they can also download it.



6

Review termly, even if nothing has changed. Contact the education provider to either arrange another meeting or let them know nothing has changed.



Dear families,

Welcome to your Individual Healthcare/Education Plan (IHP/IEP)

Every child or young person with a medical condition is entitled to an IHP/IEP. This plan outlines any additional practical, physical, social, or emotional support needed at nursery, school, college, or another education provider.

The best way to create your IHP/IEP is through a meeting with the education provider. You may wish to invite a member of your child's rheumatology team, and it's important to involve your child in developing the plan.

Because standard IHP/IEP forms don't always meet the needs of children with rheumatic conditions, this adapted version has been developed with input from charities, education providers, healthcare professionals, parents, and young people.

This pack includes:

- An IHP/IEP form for rheumatic conditions.
- Guidance notes with practical tips and solutions.
- A flow chart to guide you through the process.
- Information about Juvenile Idiopathic Arthritis (JIA). For other conditions, please consult your healthcare provider.

We hope you find this helpful. For further support or advice, please contact any of the charities listed below.

Best wishes,

CCAA – Kids With Arthritis, JIA at NRAS and Arthritis UK



Dear Education Provider,

Children and young people with arthritis or other rheumatic conditions may experience symptoms and medication side effects that impact attendance, learning, and wellbeing. Living with a long-term condition can also affect friendships and emotional health, so it's important to consider their physical, social, and emotional needs.

Standard Individual Healthcare/Education Plan (IHP/IEP) forms don't always meet these needs. This **adapted IHP/IEP** has been developed to ensure children with rheumatic conditions are fully supported to stay healthy, engaged, happy and able to reach their academic potential.

Included materials:

- Adapted IHP/IEP form for rheumatic conditions.
- Guidance notes with practical solutions.
- Additional information about the condition.

The IHP/IEP should be completed with the family in a face-to-face meeting, with healthcare professionals invited where appropriate. Please bear in mind that the conditions themselves may vary greatly from one individual to another. All children and young people with rheumatic conditions want to be treated as 'normally' as possible while being supported appropriately by the school.

As symptoms can vary and flare (a sudden worsening of symptoms) unpredictably, the plan should be reviewed regularly. Ongoing two-way communication with the family and having a key school contact are essential.

Thank you for your vital role in supporting this child or young person. For further guidance, please contact any of the charities listed below.

Best wishes,

CCAA – Kids With Arthritis, JIA at NRAS and Arthritis UK



Part 1: Contact details

Full 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	

Part 2: 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	

Part 3: Table of actions arising from discussion (please copy extra pages as required)

Topic	Action required	By whom	Date to be reviewed
<p>Examples: <i>Learning / equipment in class</i> <i>School environment</i></p>	<p><i>Subject teacher to supply extra copy of textbook</i></p> <p><i>Lift pass and friend/buddy to help carry bags</i></p>	<p><i>Subject teacher</i></p> <p><i>Responsible member of staff</i></p>	

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	Name	Signature	Date
Child/ young person			
Parents/ carers			
School representative			
Healthcare professional (if present)			

Date for IHP review: _____

Guidance Notes

Please use this list as a prompt for discussion to complete the Individual Healthcare Plan/ Individual Education Plan (IHP/ IEP) form. Each topic has suggested ideas that have helped other families. Some topics may be more relevant than others at different times in the child/ young person's educational journey. Please add topics not covered. You're not expected to be an expert in arthritis, but we encourage you to read up on the relevant type of arthritis on trusted websites (we've included some links at the end of this pack). And more importantly speak to young people and parents/carers about their individual needs and experiences.

Medication and side effects

What medication is the child on? What side effects are experienced? Going through any medication changes or difficulties? What should staff be aware of? Consider:

- A toilet pass if medication affects stomach
- Water breaks more often if medication increases thirst
- Possible nausea on injection day and strategies used to cope etc.
- Side effects if on steroids (may include: weight gain, puffy face, mood swings, irritability, 'hyper' outbursts or any other symptoms)
- Any coping strategies for side effects
- Being aware of anxieties around taking medication; medications not working as hoped or changes in medication - which may affect mood.

Hygiene, first aid and infectious diseases

Is the child on a medication that would reduce their immunity? Consider:

- School to notify parents of infectious diseases e.g. chicken pox, scarlet fever 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 handwashing if needed.
- A designated person to help apply additional sun cream at regular intervals, dependent on age/ability (some conditions and some treatments mean an increased vulnerability to the sun).

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
- Easily accessible locker
- Assistance with using mobility aids in school (e.g. wheelchair, crutches etc.)

Uniform

Does the child/ young person need any adaptations to the uniform? Are there issues with getting changed at school?

Consider:

- Shoes – supportive, comfortable and with space for orthotics (podiatrist may have recommendations)
- Shirts & blouses- buttons/ poppers
- Additional time for changing
- Permission to come into school in P.E kit on P.E days

Learning/ equipment for class, homework or coursework

Is there any impact on learning in class? Can this vary over the day e.g. more stiff and sore in the morning? Is an Occupational Therapy assessment needed?

Consider:

- Is fatigue an issue?
- Are some times of day trickier than others?
- Adaptations to learning through play at school (for younger children)
- Does the timetable need adjusting?
- Access to laptop
- Ability to move around when needed
- Agreed way for child to indicate when they need time out
- Is any specialist equipment needed?
- Positioning of chairs/desks
- Option to sit on a chair i.e. during assembly or carpet time
- Adapted pens/pencils
- Scribes
- Format of homework
- Extra set of books to be kept in school to avoid carrying them backwards and forwards to home

Physical activity

What would enable the child/young person take part fully in sports/ physical activities?

Consider:

- Agree how staff will be notified if there are problems on a day or week.
- Are there any red flag activities? (Physiotherapist might have suggestions)
- Rest breaks (how to ask for these)
- Can lessons be adapted discretely- high impact vs. low impact
- Additional time for getting changed or somewhere private to change
- The impact of weather conditions on participation e.g. cold, wet

Mealtimes

Are there any special requirements during mealtimes?

Consider:

- Medication
- Queue pass to avoid standing
- Adapted cutlery

Exams and coursework

Approaching internal or external exams, might any additional support be needed?

Consider:

- Extra time needed
- Laptop/ equipment (including typing practice)
- Software e.g. speech recognition
- Scribe
- Space to move around
- Rest breaks
- Has the child/ young person practiced using any additional support tools?
- When do you need to apply to exam boards for additional support requests?

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?

Consider:

- Trained and additional staff on trip
- Accessible room if overnight
- Storage for medication e.g. refrigerator, sharps bin
- Lifts/ wheelchair if too far to walk
- Consideration of distances and length of activities
- Assistance carrying bags or equipment
- Shade/ shelter from the sun

Social and emotional needs

Does the child/young person have any social /emotional needs that the school could help with?

Consider:

- Counsellor
- Buddy system
- Support from school nurse
- Support staff or 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?
- Support to address bullying.
- Support to communicate with peers/ school community - raising awareness about arthritis. Not all young people will want this, but it's worth considering due to the stigma around being young and living with arthritis.

Communication

What is the best way for parents, young people and education providers to communicate with each other? Consider:

- Via email
- Notebook
- Form tutor
- Phone call

How can the student alert teachers to issues without drawing unwanted attention?

How will education providers communicate information to ALL staff (including supply staff) involved with that child/young person?

How will education providers communicate when transitioning from one establishment to another?

Absences

Rheumatic conditions may require absence due to medical appointments, treatments and illness.

Consider:

- What regular appointments might the child/young person have?
- Who will take responsibility for helping them catch up any missed work?
- Buddy system for missed work
- Opportunity for remote learning
- Absences through medical appointments not to count against attendance
- One to one tutoring
- How to ensure child/young person is not unfairly penalized for absence in e.g. attendance award scenarios

Staff training

Is any staff training required?

Do you require any additional information from:

- Young person and their family
- Healthcare professionals
- Charities

Government guidance on supporting pupils in education settings with medical conditions

England

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

Scotland

<https://www.gov.scot/publications/supporting-children-young-people-healthcare-needs-schools/#page-top>

Wales

<https://www.gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf> <https://www.gov.wales/supporting-learners-healthcare-needs-0>

Northern Ireland

<https://send.eani.org.uk/what-sen>

For further information



CCAA - Kids With Arthritis are a volunteer-led charity supporting children, young people and families across England, Wales and Northern Ireland. We mainly cater for those aged 0-16 along with their families. We have 4 main strands of support for families:

- Residential Family Activity Weekends
- Local Area Support Groups
- (roughly 1 per county across England and Wales, run on Facebook, supported by our local area parent reps)
- CCAA Award Badge Scheme
- (7 different badges to collect: Courage, Effort, Supportive Sibling, Active Achievement, Research, Fundraising, Raising Awareness)
- Online and Downloadable Resources

Website: <https://www.ccaa.org.uk/>



We are a UK-wide charity supporting people of all ages living with arthritis – with dedicated work focused on children, adolescents, young adults and their families. We also have a dedicated Young People and Family Service – with a team of staff working in partnership with NHS specialist rheumatology centres across the UK to provide 121 support advice and guidance in hospital settings and communities.

Website: <https://www.arthritis-uk.org/information-and-support/understanding-arthritis/young-people-and-families/information-for-schools/>



The National Rheumatoid Arthritis Society (NRAS) was founded in 2001 and is the only UK charity specifically devoted to supporting adults and their families living with rheumatoid arthritis (RA) and children, young people and their families affected by juvenile idiopathic arthritis (JIA), and the health professionals treating RA and JIA.

Due to NRAS' targeted focus on these two conditions, RA and JIA, the society provides truly expert and wide-ranging services to support, educate and campaign for people living with and impacted by these complex auto-immune conditions.

Website: <https://jia.org.uk/>



LUPUS UK is the only national registered charity supporting people with systemic lupus and discoid lupus and assisting those approaching diagnosis. We presently have over 5500 Members and a number of Regional Groups around the UK who arrange medical talks, publish local newsletters, set up local occasions and organise fundraising events.

LUPUS UK also produces an informative national magazine with lupus articles, letters, reports, and photographs, and operates a strong Grant Programme for research purposes and welfare.

Website: <https://lupusuk.org.uk/what-is-lupus/>

