Joint Care? A report on the care received by children and young people who are diagnosed with juvenile idiopathicarthritis (JIA)

NCEPOD Report Summary for UK ophthalmologists (and eye health and care professionals).

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) has recently published findings from a national enquiry into JIA care. The report confirmed that timely diagnosis, prompt referral, and early access to medication can transform the outcomes and experience of a young person and their family. There is clear evidence that young people with JIA must have their medical, psychological and social needs supported in an age-appropriate way with access to the right professionals in the right setting.

The Royal College of Ophthalmologists fully supports the report's eight recommendations, and notes a role for UK ophthalmologists in supporting the delivery of some of these recommendations, as described below:

Recommendation 1: Raise awareness of JIA and its symptoms with those who might see patients.

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Clinicians managing children who might be at risk of JIA (such as those presenting with chronic anterior uveitis) should be aware of the signs of JIA, to ensure prompt referral to paediatric rheumatologists. The cardinal signsare:

- Painful, swollen or stiff joint(s)
- A fever that keeps returning
- Joint(s) that are warm to touch
- A limp but no injury
- Increased tiredness

Further information on JIA can be found at the following links

- www.thinkjia.org
- www.versusarthritis.org/about-arthritis/healthcare-professionals/
- www.pmmonline.org/page-1617

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Recommendation 2. Streamline and publicise local referral pathways with clear measurable timelines for patients with suspected juvenile idiopathic arthritis.

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The report recommended the development (in line with the UK guidance on JIA uveitis surveillance, available here) and implementation of agreed referral pathways from rheumatology services to ophthalmology clinics (including same day/ combined clinics) with clear standards for referral and follow-up timeframes.

Recommendation 3. Provide timely access to appropriately trained physiotherapy, occupational therapy, pain and psychology services at the diagnosis of JIA, and then as needed through adolescence and adulthood.

Recommendation 4. Offer age-appropriate information about juvenile idiopathic arthritis and medication risks and benefits to patients and their parents/carers at diagnosis and on an ongoing basis.

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This includes age-appropriate information about the associated uveitis. Clinicians may find this co-developed patient video helpful.[1]

Recommendation 5. Provide training to the patient, if age-appropriate, and/or their parents/carers on how to administer subcutaneous injections for juvenile idiopathic arthritis at the point treatment is initiated.

Recommendation 6. Ensure timely access to intra-articular steroid injections by staff who have been trained to deliver age-appropriate care in units where local or general anaesthesia can be delivered.

Recommendation 7. Provide a holistic, developmentally appropriate rheumatology service for patients with juvenile idiopathic arthritis.

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High quality youth work, self-management opportunities and family support can make a significant difference to many young people and their families, especially at diagnosis, during flare ups, and at the time of transition to adult care.

1. Allocate sufficient time in review appointments to:
    a. ask patients (or their parents/carers if age-appropriate) about their physical health, mental health (moods, feelings, worries, concerns), educational/social/work-related concerns and signpost them to support services.
    b. signpost to educational resources/support for parents/carers as well as developmentally appropriate resources for children, young people and young adults covering range of topics including life skills
    c. use ‘apps’ and text messaging to inform patients about JIA and associated conditions, to allow them to monitor their symptoms - incorporate discussions about the transition between child and adult services, see ‘The Inbetweeners’ report

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2. Run combined clinics with the paediatric and adult rheumatology teams; members of both should be present for at least one visit before transfer. Involve members of the wider MDT who understand or are trained in the needs of adolescents (not just paediatrics or adult healthcare) and follow adolescent best practice.
3. Provide opportunities for adolescent patients to be seen alone

Recommendation 8. Develop NICE guidance for the management of juvenile idiopathic arthritis.

Additional references:

1. Khalil et al. Show don't tell: assessing the impact of co-developed patient information videos in paediatric uveitis. Eye (Lond). 2024 Feb;38(2):246-252. doi: 10.1038/s41433-023-02659-w
2. Screening for Uveitis in Juvenile Idiopathic Arthritis (JIA) RCOphth, 2006 https://www.rcophth.ac.uk/resources-listing/guidelines-for-screening-for-uveitis-in-juvenile-idiopathic-arthritis-jia/

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