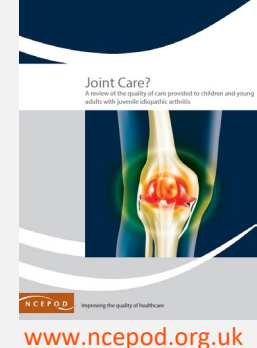


The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is a charity that works to make healthcare services better for the people who use them. We do this by collecting information from people who have used healthcare services. Our work has led to lots of positive changes in how healthcare is provided.

We collected information from hospitals, GPs and patients and their parents/carers to see how care for children and young people with juvenile idiopathic arthritis (JIA) could be made better.

For information about JIA visit:

VERSUS ARTHRITIS
NATIONAL RHEUMATOID ARTHRITIS SOCIETY
JUVENILE ARTHRITIS RESEARCH
CHILDREN'S CHRONIC ARTHRITIS ASSOCIATION
NHS



WHAT WE FOUND

JIA symptoms were not always recognised, which may have meant a delay in referral to a specialist.

When JIA was suspected it was not always clear who a patient should be referred to.

Patients/parents/carers did not always get trained to administer methotrexate, which may have led to a delay in treatment starting.

Many patients continue to have JIA as adults but access to physiotherapy, occupational therapy, pain and psychology services was not always available.

A focus on healthcare meant that other aspects of wellbeing and education, were not always addressed, such as having to miss school for appointments.

WHAT HEALTH SERVICES CAN DO

Make healthcare professionals aware of JIA symptoms, to prevent delays to treatment starting.

Make pathways clearer, to ensure the patient sees the correct specialist at the correct time for their needs.

Provide training for patients and parents/carers on how to inject medications for JIA.

Provide patients with access to support services, physiotherapy, occupational therapy, pain and psychology services as needed.

Provide a service which is appropriate for patients at different stages of development.

WHAT YOU AS A PATIENT/PARENT/CARER CAN DO

If you or your child have symptoms of JIA – tell your doctor or healthcare team.

SYMPTOMS MAY INCLUDE:

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

If you've been told you will need to inject your/your child's medication, ensure access to training is available and you are provided with additional resources such as online instructions.

If you are under the care of doctors who treat adults, ask for a referral to other services such as physiotherapy if you need it.

Ask if you can have appointments outside school/work hours, or online if you don't need to be at the hospital, or if appointments for different doctors for example joints and eyes could be on the same day.