

British Paediatric Rheumatology Group

Standard
Assessment for

*Juvenile
Idiopathic
Arthritis*

The Assessment & Evaluation Process

Assessment

Aims of Treatment

Interventions

Evaluation

Introduction

This booklet is aimed at those professionals who assess only a small number of children with Juvenile Idiopathic Arthritis (JIA) in either a hospital or community setting.

In order to plan effective management of children with (JIA) the assessment should encompass the physical, psychological and social impact of the disease on the child and the family. All disciplines involved will base their practice on existing local and national standards and codes of conduct.

The aim of the booklet is to formulate a comprehensive set of data. Ideally it is the responsibility of the whole team and care should be taken to avoid unnecessary overlap in obtaining information about a child.

This forms the initial assessment, which can be carried out over a number of sessions by various members of the multidisciplinary team.

Information gained should be used to establish a comprehensive management programme and subsequently for re-assessment.

The information in this booklet has been compiled by a multidisciplinary group of specialists in Paediatric Rheumatology and is the recommended assessment for children with JIA, as endorsed by the British Paediatric Rheumatology Group (BPRG).

Initial Assessment

The assessment begins when the child and family enter the room, by observing

- Independence of the child
- Body language
- Family dynamics

Consideration must be given to age appropriate development and behaviour.

SUBJECTIVE:

History of Present Condition

From onset:



Symptoms

When they started, what they were, any precipitating factors e.g. Spiking fever, rash, mouth ulcers, headaches, sore throats, trauma, travel abroad or vaccinations.

Differentiates between diseases and subtypes of JIA. Giving an indication of severity and speed of onset of disease, length of time of symptoms and possible precipitating factors.



Other Professionals involved

Provides a picture of previous experiences of hospital and different professionals seen and diagnosis given. An indication for other issues e.g. pain amplification.



Previous hospital admissions

Dated chronologically, with details of investigations.

Clarification of previous investigations and treatments as this may influence future management.



Length of time to diagnosis

To identify the pathway taken to come to a diagnosis, and whether the disease was untreated for a significant period of time, resulting in physical and psychosocial complications..



Any previous diagnosis given

To ensure that the clinician is aware of the diagnosis given, its

implications and the family's understanding.



Treatment

Establish what treatments have been given from the onset (including complimentary therapies) adherence and response.

Direct future management.

Presenting Problems

It is important to establish when the changes occurred during the progression of the disease. The longer the time from onset, the greater the likelihood of clinical changes.

The current problems need to be established within a relevant time scale, e.g. in the last month.



General function

Establish what activities they are able to do now, compared with previously. What difficulties they have with Activities of Daily Living (ADL).

To consider the impact of the disease on function..



Early Morning Stiffness (EMS)

How severe, for how long and which areas of the body are affected. Establish whether there is stiffness at any other time in the day.

EMS is an indication of disease activity. Stiffness at other times of the day may indicate other issues e.g. evening stiffness is often an indication of muscle fatigue.



Pain

An accurate description of the areas affected, type, severity, intensity, how long it lasts, what relieves the pain and what exacerbates it? Consider other expressions of pain, e.g. avoidance, behavioural issues.

Needs to be taken into account when managing treatment.



Other



Child's main concerns

Discuss main concerns and effect on daily life.

This ensures that intervention is client centred.



Parents' main concerns

Discuss main concerns and effect on the child and family.

To ensure that parental concerns are incorporated into the

management plan.

Past Medical History



Birth History

To establish any other pathology.



Developmental History

Timing of normal milestones.

Relevance of milestones being affected by disease.



Immunisations

Establish immunisation history.

Some vaccines may be contraindicated if immunosuppressive drugs or steroids are needed.



Previous illness/conditions/trauma/allergies

Record any persisting to present time.



Surgery

Previous or planned.

Drug History



Previous/Current

Ask about all drugs taken, including dosage, method of administration, dates started and finished (if known), effectiveness, side effects and allergic reactions.

To assist in future drug planning and to be aware of any needle phobia, difficulty swallowing etc.



Include homeopathic and herbal medicines

Social History and Family History



Family Tree

Determine the relationships in the immediate family and who lives at home.

It is important to have a picture of the family dynamics to establish potential constraints and support systems.



Occupation of parents

Establish working practices, time demands etc.



Other carers/important relationships

This may include relatives (e.g. grandparents) childminder, crèche

staff, foster care, partners, close friends.

To ensure everyone involved with the child has an understanding of the disease and it's management.



Family illness

Ask about diseases/illness within the family e.g. diabetes, arthritis, psoriasis, GI problems, chronic pain and other conditions. Note blood relatives.

May have significance in diagnosis, psychological adjustment and perception of condition.



Accommodation

Type of accommodation, ownership, stairs, general access and layout.

This may highlight the need for any adaptations and provides information when sources of funding are being examined.

Ethnic and cultural concerns



Culture

Awareness of cultural issues in relation to the disease.



Religion

Awareness of religious practice and any problems relevant to JIA.



Language

Establish the language spoken by child and family and whether an interpreter is required. Preferably not a family member or friend.

Ensure interpreter can give a clinically accurate & effective interpretation.

Benefits

Ask if they are in receipt of any benefits or are in the process of claiming.

To establish whether appropriate financial support has been provided. A referral to a Social worker maybe appropriate. (Lady Hoare Trust)

Activities of Daily Living (ADL)/Function



Personal Care

Establish level of independence, help required, assistive devices or equipment needed.



Eating/food preparation



Walking/mobility

Distance, time, speed, standing tolerance and balance.

Also note if they are able to keep up with their peers/family and

enquire as to whether any aids e.g crutches, wheelchair are required, why, when and for how long.

It will give a good base line assessment that can be used as an outcome measure.



Stairs

Level of independence, method of ascent and descent, use of banister rails and walking aids.



Transfers

Any equipment in use or required or assistance needed.

Play, Hobbies, Interests and Socialisation



Play, actives, individual hobbies

Activities that the child likes to do, including any that have had to be stopped due to this illness.

Determine affect of disease on child's everyday life and may assist in goal planning and setting up a treatment programme to regain ability.



Family hobbies

Include any that they are unable to do now due to this illness.



Sports

Establish level of participation in individual sport and note reasons for change.

To ascertain level of fitness and socialisation, and to determine what advice has been given.



Socialisation

Enquire about peer interaction, friends and acquaintances.

Are they developing normal relationships within peer group.



Drugs/alcohol/sexual activity

This needs to be age appropriate.

Note interaction with second line drugs and risks associated with pregnancy. Refer to other agencies if appropriate.

School



Name and address of school



Private or state



Name of the local authority



Name of school doctor or community paediatrician



Name of Special Educational Needs Co-ordinator (SENCO) and or appropriate teacher e.g. form teacher, head of year.



Gain agreement from parents to contact the school.

It is important to consider the impact of arthritis on the child's school experience and access to the curriculum.

It is a legal requirement to gain permission from the parents before contacting the school about their child. For each new school attended, permission must be gained.

NB if the child is deemed to be Gillick Competent, they must be asked for their permission.



Year group exams

Check when they are planned and whether extra time/help is required.



Attendance

Enquire about attendance record. explore the reasons why they may have missed any time from school and any consequences e.g held back a year.



Transport

Ask about distance to school and method of transport. Are there any problems getting to school or on arrival.



Help provided

- Equipment e.g. laptop, sloping desk, foot rest
- Assistance e.g. to scribe, help with physiotherapy programme, with carrying bags
- Adaptations to environment e.g. ramps, rails, moving furniture
- Personal ADL e.g. changing for PE, toilet



Customised school provision

Enquire if the child has been identified as requiring special provision at school e.g. statement of special needs. This may vary in different authorities. When the last review took place and who was involved.

It may be necessary to formulate special provision following local guidelines and liaising with family.



Access & mobility around the school

Accessibility of facilities e.g. toilet, canteen, classrooms.

Consider distance, stairs, safety issues etc.



Writing

How long can they write for; legibility, speed, limiting factors.

Establish the need for assistance in taking notes (dictaphone, scribe)



Science, technology and IT

Any specific problems (seating, standing, lifting, grip, fine motor skills).



PE/Games

What they usually do during PE or games. Do they participate fully or is involvement limited and what are the alternatives.



Play/break time

Do they join in with their friends? Any specific problems e.g. carrying lunch tray, cutting food, chewing, time constraints.



Rest facilities

Is there access to medical/rest room?

Is the child able to stay at school rather than being sent home.



Trips/outings/extra curricular activities

Are they able to participate? How co-operative is the school?

Are they a contributing member of their peer group?

Career planning/development

Have they been encouraged to participate in household chores, part-time jobs, voluntary work. Discussion in the area of careers is important from a relatively early stage in secondary education. Do they have access to a careers advisor.

To establish the level of responsibility and independence. This will help establish whether their career goals are realistic in the light of the arthritis and if they need help to find career advice.

What information has been given?

Establish the information they have already been given about the disease and it's management and where they received it from..

Level of understanding of disease

Discover what the child and their family understand about the diagnosis, it's treatment and it's implications.

Impact of diagnosis

Family support

Establish child and family need for information and psychological support.

Occupational Therapy / Physiotherapy



Previous therapy

Previous contact, advice, interventions and the outcome.



Present therapy

Details of current intervention.



Home programme

Gain details of the home programme of exercise, activity, splints and orthotics. Ascertain adherence and level of supervision.



Name and contact details of any other therapists involved.

To communicate current treatment programmes to others.

Other Professionals

Include community and hospital based teams that are commonly involved;

- ⇒ GP
- ⇒ Dietician
- ⇒ Ophthalmologist
- ⇒ Orthotist
- ⇒ Podiatrist
- ⇒ Psychologist
- ⇒ Social Worker
- ⇒ Surgeons

This list is not exhaustive

Include details about their involvement and the support they provide, as well as any contact details.

To ensure that appropriate liaison occurs between professionals.

OBJECTIVE:



Baseline measurements:

Height/Weight/Centiles/Urine/Blood Pressure



Visual Analogue Scale (Pain)

Visual analogue scale for pain completed by both child and parent and also record who filled it in. (Varni)



Visual Analogue Scale (Global Assessment of Disease & Function)

Visual analogue scale for the perceived level of disease activity at the present time, completed by either child if old enough, or parent. It may be useful for the clinician to record the perceived level of activity, by using the physicians' global assessment.

Joint and soft tissue examination



Observation

- Skin discolouration

- Muscle bulk (this can be measured objectively, but care must be taken to account for joint swelling)
- Reaction to pain
- Swelling
- Bony changes
- Subluxation
- Joint deformity



Palpation

- Temperature
- Stability of joint
- Crepitus
- Swelling
- Muscle spasm
- Joint margin pain
- Enthesitic pain



Range of movement of each joint, including spinal movements

- Range of movement - active and passive
- Fluidity of movement
- Range of movement end feel
- Range of movement limited by deformity
- Compare (L) and (R) - be aware of hypermobility
- Record hand and leg dominance. Has this changed since onset of disease?

N.B. Note time of assessment as the findings will often differ depending on time of day

Muscle Strength

An objective measurement of the main muscle groups should be recorded. Muscle testing can be a useful outcome measure for effectiveness of treatment. This should include a measure of grip strength, there are a various pieces of equipment on the market which can be used.

Observation of general movement and function

ADL Assessment

Therapists need to analyse activity to determine whether physical, psycho-social or environmental factors are limiting function. Specific problems should be analysed in the most appropriate environment (school, home)

Functional questionnaires

There are a number of disease validated outcome measures

- JAFAR (Juvenile Arthritis Functional Activity Rating)
- JAQQ (Juvenile Arthritis Quality of Life Questionnaire)
- CHAQ (Childhood Health Assessment Questionnaire) (2)
- CHQ (Childhood Health Questionnaire)

Posture and Gait

Observe posture in static and dynamic situations, looking at position of individual joints. Note any familial tendency. Leg lengths should be checked as there may be a discrepancy.

A record of gait can be kept by means of:-

- Video
- Pressure plate
- Painted feet
- Gait laboratory

Stamina

- Subjective (generally used)
- Timed walk test e.g. 6 minute or specific distance, which should be repeatable.

Splints/Orthotics

Give details of any splints/orthotics that have been provided. Check if they still fit, how often they are being used and who provided them and their contact details.

Wheelchairs

Is a wheelchair used, when do they use it, who assessed them, what types of chair, how is it maintained, what difficulties do they have with it?

Finding level of independence, whether the chair is suitable for the individual child.

References

1. Singh G, Athreya BH, Fries JF, Goldsmith DP. Measurement of Health Status in Children with Juvenile Rheumatoid Arthritis. *Arthritis and Rheumatism* 1994; 37(12): 1761-1769
2. Nugent J, Ruperto N, Grainger J, Machado C, Sawhney S, Baildam EM et al. The British Version of the Childhood Health Assessment Questionnaire (CHAQ) and the Child Health Questionnaire (CHQ). *Clinical and Experimental Rheumatology*. In press.
3. Landgraf J, Abetz L, DeNardo B, Tucker L. Clinical Validity of the Child Health Questionnaire - Parent Form (CHQ-PF) in children with juvenile rheumatoid arthritis. *Arthritis and Rheumatism* 1995; 38:5795.
4. Langraf J, Abetz L, Ware J. A Users Manual. The Child Health Questionnaire. The Health Institute, New England Medical Centre, Boston, MA : 1996.
5. Duffy CM, Arsenault L, Watanabe Duffy KN, Paquin JD, Strawczynski H. The Juvenile Arthritis Quality of Life Questionnaire: Development of a New Responsive Index for Juvenile Rheumatoid Arthritis and Juvenile Spondyloarthritides. *Journal of Rheumatology* 1997; 24(4): 738-746.
6. Lovell DJ, Howe S, Shear E, Hartner S, McGirr G, Schulte M et al. Development of a Disability Measurement Tool for Juvenile Rheumatoid Arthritis, The Juvenile Arthritis Functional Scale. *Arthritis and Rheumatism* 1989; 32(11): 1390-1395

Acknowledgements

Nurses, Occupational Therapists and Physiotherapists who are members of the British Paediatric Rheumatology Group, Allied Health Professional group from the following hospitals:

Alder Hey Children's Hospital, Liverpool

Birmingham Children's Hospital NHS Trust, Birmingham

Great Ormond Street Hospital for Children NHS Trust,
London

Heatherwood and Wexham Park Hospitals NHS Trust

Leeds General Infirmary, Leeds
Middlesex Hospital, London
Queen Alexandra Hospital, Portsmouth
Queens Medical Centre, Nottingham
Royal Hospital for Sick Children, Edinburgh
Royal Victoria Infirmary, Newcastle Upon Tyne
South Peterborough Primary Care Trust
Wrightington Hospital NHS Trust, Wigan

Produced by:

Draft: March 02