



Allied Health Professional (AHP) Standards of Care for Juvenile Idiopathic Arthritis

These Standards of Care were prepared by the AHP group of BSPAR, adapted from the BSPAR Standards of Care for Juvenile Arthritis developed by the Clinical Affairs Sub-committee and should be read in conjunction with them.

Aims:

This document is designed to help and support paediatric Allied Health Professionals by providing a statement of the standard of care in the management of children and young people with Juvenile Idiopathic Arthritis (JIA), irrespective of geographical location. It should also be read in conjunction with A Standard Assessment for Juvenile Idiopathic Arthritis (BSPAR AHP Group)

Objectives:

1. To work in partnership with the children and young people with JIA, their families and other members of the multidisciplinary team including local, regional and national services, as well as school, social services, other agencies and voluntary organisations to ensure a seamless service. This is to ensure the child and family positively adapt to the diagnosis of JIA and to empower them to maximise their potential in all aspects of their lives.
2. To devise individual holistic packages of care, incorporating developmentally appropriate physical and psychosocial aspects of management of children and young people with JIA.
3. To utilize evidence based clinical care for children and young people with JIA.

Standards:

1. The Multidisciplinary team.

All children and young people with JIA should have access to a multidisciplinary team who are competent in the management of children and young people with JIA. This should include occupational therapists, paediatric nurse specialists, physiotherapists, play therapists, podiatrists/orthotists, psychologists and social workers. All AHP members of the team should work in partnership with the child and their family, each other and with the wider MDT,

2. Waiting Lists

Once diagnosed, patients with JIA should have an urgent AHP assessment in order to minimize complications of the disease, such as contractures, muscle weakness and reduced fitness, and to reduce the impact of the disease on childhood development, school attendance, etc. A management programme should be planned in conjunction with the patient, carers and MDT with regular reviews

3. Communication

Effective communication links with all professionals involved in a patient's care is vital for optimal management of the disease and its effects. This may include hospital and community teams, school and social services.

4. Inpatient Management.

All patients with JIA who are admitted to hospital should be housed in age appropriate accommodation. They should be referred to the Paediatric Rheumatology multidisciplinary team for holistic review. Appropriate access to specially designed facilities for washing and toileting for persons with disabilities is required, including access for wheelchairs. (Charter for Disabled Persons Using Hospitals, 2002, NSF for Children, 2003).

5. Outpatient Management

Children and young people with JIA, should be assessed by the multidisciplinary team using the "Standard Assessment for JIA" (BSPAR, 2003) as soon as possible after diagnosis. Care should be taken to avoid excessive absences from school for hospital appointments, so combined visits should be arranged where possible.

Regular treatment sessions should be arranged after school hours where possible and should be kept to a minimum with least disruption to patient and family routine

6. Musculoskeletal management.

All children and young people with JIA should have a full musculoskeletal assessment and be provided with the skills to optimise their joint range of movement, muscle strength and fitness to minimize the impact of disease.

7. Management of occupational performance.

All children and young people with JIA should have assessment of their occupational performance including self-care, school, productivity and leisure. Steps should be taken to optimise function which may include advice, treatment, and modification of their environment.

8. Pain management.

All children/young people should be assessed to establish their level of pain and coping strategies. Children/young people and their carers should be equipped with a range of skills and strategies to manage their pain more effectively.

9. Understanding of chronic disease.

All professionals involved with children and young people with JIA should have a good understanding of the prognosis and development of chronic disease including the physiological, psychological and social and cultural impact on the child/young person and their family, and should be able to adapt their interventions appropriately. They should also be aware of issues specific to JIA, such as the day-to-day variability of the symptoms. A psychosocial assessment should be made and strategies developed to address issues identified.

10. Care of adolescents.

An individualized transition plan should be in place to ensure a seamless transition from paediatric/adolescent to adult services. The adult service should include allied health professionals who have adequate knowledge of the needs of adolescents, and of JIA and its implications into adult life.

11. Empowering patients with JIA and their carers.

All patients with JIA should be empowered by providing developmentally appropriate information using a variety of media. This should include information of the disease and its management, health and lifestyle choices. Intervention should be child/young person centred so that the child/young person is an active participant in treatment planning.

12. Health promotion for children and young people with JIA.

All young people should have access to a wide range of generic health information appropriate to their age and understanding.

13. Knowledge of voluntary organisations

All AHPs working with children and young people with JIA should be aware of local and national voluntary organisations, such as Children's Chronic Arthritis Association (CCAA), Choices, and Arthritis Care.

14. Regular review.

All patients should have regular assessments to identify their current and future needs. This may include a review of treatment options, for example, drug regime, exercise programme and lifestyle advice.

References

BSPAR (2003) A Standard Assessment for Juvenile Idiopathic Arthritis. www.bspar.org

Department of Health (2003) Getting the Right Start: National Service Framework for Children.

Approved by BSPAR Executive June 2007
Review 2008
JMS 2007