New Insights in the care and management of JIA

Supporting Children and Young People with Juvenile Idiopathic Arthritis in Schools, Colleges and Other Educational Settings Through School Toolkits

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Background: Juvenile Idiopathic Arthritis (JIA) is a heterogenous group of auto-immune disorders characterised by chronic joint inflammation, affecting children and young people (CYP) under the age of 16. CYP with JIA experience considerable physical and psychological impacts due to their condition. CYP spend a considerable amount of time at school, college or other educational settings. Whilst most CYP with JIA are able to access education, many require adaptations, awareness of their needs, or specific support to enable them to fully engage in learning. Families of CYP with JIA have reported a lack of awareness and understanding, and requested resources to enable schools to support their children in school.

Objectives: The aim of this work was to develop a School Toolkit to allow teachers and other school staff to confidently support CYP with JIA, and to assess its initial rollout.

Methods: Using a network of parents of CYP with JIA, including those with experiences in working in educational settings, UK-based charity Juvenile Arthritis Research developed a resource aimed at schools, colleges, pre-schools and other educational settings: a Toolkit of information and resources. Given awareness of childhood arthritis is low, the Toolkit includes awareness-raising resources, aimed both at staff and all families connected to the school. Increased awareness can help improve diagnosis times and timely access to treatment in those not yet diagnosed. In addition, the Toolkit contains information about what JIA is, resources for schools to provide targeted interventions, and information on how schools can successfully support CYP with JIA. Finally, each Toolkit contains both a presentation for explaining arthritis to children in a classroom or group assembly setting, and a training presentation for delivery to staff, as well as digital copies of key materials and awareness-raising resources for distribution to parents and families. Recipients were invited to complete a short web-based survey to review the Toolkit.

Results: In the first six months after launching the new School Toolkit, around 100 Toolkits have been sent to schools in the UK, potentially providing information that arthritis affects children to over 100,000 families. Schools have advised they are using the resources in their settings, including giving lessons to children to explain what arthritis is, putting up posters highlighting the key signs and symptoms of JIA, and utilising the staff training resources. Feedback from schools was entirely positive, with one teacher reporting “Wow- it’s fantastic. The student presentation is particularly impressive with how it translates all the key information in a child-friendly manner.”

Conclusion: The development and supply of a Toolkit specifically for use in schools and colleges has helped raise awareness that children get arthritis, and provided resources to train and support school staff enabling them to confidently support CYP with JIA. Utilising the experience and skills of parents and teachers in the development of the Toolkit has ensured all resources are relevant and address the needs of both families and schools. Toolkits can be requested free of charge by schools in the UK from www.jarproject.org/toolkit.