

Information for schools about Arthrogyryposis

What is Arthrogyryposis (AMC)?

Arthrogyryposis Multiplex Congenita (AMC) is a term used to describe conditions where limitation in the movement of a joint or multiple joints is present at birth. Most children with Arthrogyryposis are not intellectually impaired and do not have sensory problems or learning difficulties. The condition is neither progressive nor contagious. Although arthritis may develop in later life, Arthrogyryposis is not primarily an arthritic disorder.

Management of Arthrogyryposis

Many pupils and students with Arthrogyryposis will have had extensive Physiotherapy and Occupational Therapy since birth to stretch tight joints and to strengthen small weak muscles. Splints are often used to help improve or maintain the position of affected joints and aids used to improve function in activities of daily living.

A number of pupils and students will have had orthopaedic surgery to reposition joints and allow more functional sitting, standing and walking. Surgery for hip and knee contractures (dislocations) and for club feet contractures is usually carried out in infancy or pre-school years and may not be mentioned by parents at school entry.

At school entry hand function issues are usually more obvious. Hand surgery may be useful, particularly to reposition the thumb tendons although scarring may be a problem in some students and pupils with Arthrogyryposis. It is best to allow a considerable period for assessment of individual and bi-manual hand function and opportunity to practise skills. Many students with Arthrogyryposis are most capable with their hands, even though their hands look to be significantly affected.

The child with Arthrogyryposis at school

For most pupils with Arthrogyryposis, intelligence and learning abilities are unaffected, although the student may be restricted by his or her motor skills, particularly in timed classroom tests. Implications vary with the severity of the Arthrogyryposis.

Hand function

If the main difficulties are with the upper limb and/or hand function, assessment by a Paediatric Occupational Therapist may be very useful, particularly at transition periods such as: before joining pre-school provision; before school entry; before entering secondary education and before moving into further education. School performance can be enhanced significantly by careful attention to:

- seating
- desk height and slope
- posture
- writing tools
- specific aids such as loop-handled scissors

Computers

Many students will benefit from using computers and laptops in class. Special keyboards and wrist supports are available. Occasionally, individualised equipment may be needed. There are an increasing number of software programmes on the market that might help with recording work e.g. voice recognition programmes, text prediction (including in modern foreign languages), on screen keyboards.

Fatigue

Fatigue is a common problem which is mainly due to small muscles, poorly placed joints and restricted joint movements. Lessons requiring significant hand function may

need to be 'spaced' by verbal responses or stencils used to encourage writing of only the most significant responses. Sometimes the best option might be scribing by a Learning Support Assistant.

Outside the classroom, fatigue may limit participation in physical education, sport or excursions. Participation up to a student's ability level will encourage bone and muscle strength but it is important not to let the student become overtired. Limbs may become painful and tiredness hinders learning.

Lower limb difficulties

Students with extensive lower limb involvement may need support to move to and from classrooms, toilets and play areas. Home transport may also be an issue.

A wheelchair may be useful for covering longer distances, such as on excursions, even if it is not needed at other times. Equally, as a pupil moves into secondary education and thus to a larger school they may need to use a wheelchair more often, or start to use one, in order to keep up with their peers and to be able to carry their books etc. Energy is best conserved for learning and as pupils grow the weight increase may make walking very tiring.

For those pupils and students affected in upper and lower limbs a powered chair might offer a better (and sometimes the only) form of independent mobility. Being able to move around without the help of a 'pusher' will also give them more opportunity to mix socially with their peers.

Vocational implications

Students should be encouraged from a very early age to develop their cognitive and social skills. Their musculo-skeletal problems do limit

their vocational choices, although people with Arthrogyposis are definitely employable.

Other points to be considered when supporting a student with Arthrogyposis

- Pupils and students with Arthrogyposis (AMC) should be treated the same as their peers whilst Physiotherapy, Occupational Therapy and medical resources used to assist them – particularly at school entry and transitions
- Children and young people should be involved in decisions about their education, treatment and any other aspect of their life which may be affected by their AMC
- Cognitive and social skills at levels appropriate to the student's age should be encouraged
- Having the help of an adult in the classroom or at recreational times can hinder a pupil/student's interaction with peers and impact negatively on their potential to make friends – helpers must 'stand back' whenever they are not needed
- Pupils and students with AMC should be afforded the same privacy as their peers: no discussions on any issues concerning the pupil/student should take place in earshot of those not involved in the conversation – whether staff, pupils or other
- If the child or young person needs support with personal care: involve them in the planning of that care; always ask them permission before helping; ensure that they feel in control and that they have a sense of ownership of their body
- **People with AMC tend to be bright, articulate and very determined to 'succeed'**



The Arthrogyposis Group | 45 Milton Road | Hanwell | London | W7 1LQ

Tel: 0800 028 4447 | www.taguk.org.uk

Registered Charity No. 327508