

When your baby has Arthrogryposis

A Guide to Services and a Glossary of Terms



It can seem very daunting when you give birth to a baby with additional health needs, especially as many people may become involved in the care of your child and the management of their

Arthrogryposis. Below is a list of some of the doctors, therapists and other professionals that you might come into contact with:

- **A health visitor** – to suggest practical ways of coping with caring for your child and to give you information and advice on day-to-day problems
- **An occupational therapist** – to support you in helping your child manage daily tasks, such as dressing, washing and going to the toilet. They can also give advice on – and sometimes arrange for you to be supplied with – aids, equipment and adaptations to your home to make life easier and to promote your child's independence and mobility
- **A physiotherapist** – to provide treatment and advice to help increase joint and general mobility. They can also give you advice, for example on lifting your child correctly
- **A speech therapist** – to help children who have speech, language or communication problems
- **A child development centre or unit** – to assess your child's developmental needs and organise therapy or services if appropriate
- **An orthopaedic consultant** – to provide treatment for bony or skeletal problems
- **A genetic counsellor or consultant geneticist** – to help identify the type of Arthrogryposis and whether it is a genetic condition
- **A consultant neurologist** – to identify and treat any problems of the nervous system
- **A paediatric consultant** – to generally oversee the healthcare received by babies and children. They will often make referrals to specialists

Glossary of Terms Associated with Arthrogryposis

AMC: Arthrogryposis Multiplex Congenita

Flexed/flexion: bent/close to the body

Amyoplasia: Type of AMC that is sporadic and thus not inherited and which usually only presents with symmetrical contractures of limbs

Casting: placing affected joint in plaster of paris to improve its position. Removing after a period of a week/s and placing the joint in an improved position before applying more plaster of paris

Central nervous system: brain/spinal cord

Distal Arthrogryposis (DA): a group of disorders that are hereditary and that usually tend to affect just the 'distal' joints, i.e. hands and/or feet. The various types of DA have other symptoms too, e.g. cleft palate, scoliosis, facial involvement etc.

Extended/extension: straight/away from the body

FOs: Foot orthosis

HKFOs: Hip, knee and foot orthosis

Ilizarov frame: an external fixator (metal frame) attached to a joint contracture for a period of time and repositioned regularly to improve position of the affected joint

Joint contracture: fixed or stiff joint

KFOs: Knee and foot orthosis

Micrognathia: abnormal smallness of one or both jaw bones

Osteotomise / Osteotomy: ("bone cutting") – a procedure in which a surgeon removes a wedge of bone near a affected joint

Orthosis: support of weak or ineffective joints or muscles with a splint, brace or calliper

Pathology: compilation of abnormalities

Plantigrade: foot flat to the floor, i.e. Foot at right angle to leg

Ponseti Method: treatment of clubfoot through manipulation and casting, followed by boots with a bar

Scoliosis: curvature of the spine

Splint: material or a device used to protect and immobilise a body part, i.e. in AMC to maintain or improve position of a joint

Talectomy: taking away some of the talus bone which is found in the heel of the foot

Talipes: clubfoot

Tracheotomy: the surgical operation of cutting into the trachea especially through the skin

Trismus: spasm of the muscles of mastication/jaw



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