

Talking to your child about Arthrogryposis

How can I explain to my child about their AMC?

The information on the following pages and which is aimed at older children and young adults with AMC, might help you to come up with the right explanations about AMC for your child. You may need to adapt some information so that it is at the best level for your son or daughter's age and understanding.

All children and families are different and what works for some may not work for others. What feels right for you and your child is very important. The following suggestions from parents and disabled people may help:

- Encourage your child to learn as much as possible about their AMC as they get older
- Remember that as your child gets older the explanations and responses will need to change
- All close family members should be able to explain in a similar way and younger siblings need to have an explanation about AMC too
- Listen to your child's worries and concerns
- Encourage your child to talk to you about anything and everything – that way they will feel more comfortable to ask questions and to talk to you about their AMC
- Involve your child in decisions on treatment etc. as much as possible
- Try not to talk about your child and/or their disability as if they were not present. This

often happens in medical appointments

How can I help my child to accept their disability?

Research, including a TAG Survey on Growing Up, shows that some people have difficulty in coming to terms with being disabled. For some it takes a long time. A parent's role in supporting their child through this process is very important and you can help your child accept their disability in many ways:

- Reinforce with your child the fact that everyone is different
- Be generous with compliments
- There are more and more positive disabled role models in the media – point them out to your child without making too much of an issue. And don't forget all the excellent role models in TAG! Not only are many of TAG's key-workers adults with AMC but we have other great achievers in our membership too (see page 4)
- Encourage your child to mix with other disabled children, even better if they can meet and mix with others with Arthrogryposis. Don't forget TAG runs a TAG Camp and a TAG Weekend each year, whilst Regional Contacts may put on get-togethers more local to you. TAG also has an email list of nearly two hundred members and you can always request an up-to-date contact list of members in your area. The list includes telephone number, address and the name and age of the family member that has AMC.



How can I help my child deal with awkward questions about their AMC?

- Help your child prepare for any difficult questions about his or her AMC that they are likely to be asked – especially by their peers
- Help your child to develop diversion tactics for any questions about their disability that they choose not to answer e.g. by changing the subject
- Teach your child some simple sentences about their disability e.g. “It’s just the way I was born”; “When I was in my mummy’s tummy I stopped moving for a while so my joints got stiff”; “It’s just the way my arms/legs are”. You and your child may find a different explanation that you prefer. Encourage your child to practice until they can explain about their disability confidently
- Some families find role play a useful way of practising these sentences
- Remember that there are certain times in a disabled child’s life that they are more likely to be asked questions about their disability e.g. changing schools, joining out of school

clubs, going on holiday. It might be good to discuss and prepare your child for those occasions

- If your child is being called names or teased take it seriously. When it is happening at school, speak to the relevant member of staff about it, as this is a form of bullying

If you have any questions at all about Arthrogyposis or TAG, please do not hesitate to contact the National Contact Officer, any of the Trustees or your Regional Contact. Details for each can be found on the inside cover of the national newsletter, TAGTalk, or by contacting Head Office (see contact details below).

If you would like details of the next TAG Weekend or TAG Camp, please contact Head Office. Equally, please email or ‘phone the National Contact Officer if you would like contact with other families in a similar situation to you and your child – either by receiving an up-to-date regional member list or by being added to the member email list. Contact details on back page.

About AMC

What is AMC?

Arthrogryposis Multiplex Congenita is also known as Arthrogryposis or as AMC and is used to describe stiff and fixed joints in more than one part of the body. Sometimes people are affected in arms and legs, sometimes just arms or just legs. Other people are also affected in their spine or jaw and may be affected in other ways too.

How did we get AMC?

Some people have been told that they have AMC and been given no other name for their condition. Meanwhile, others have been told that they have a specific condition and also have AMC. This is because there are many different conditions that have fixed or stiff joints (AMC) as one of the symptoms, and they have other symptoms too. Some of the main conditions that have AMC as a symptom are:

- Amyoplasia
- Distal Arthrogryposis
(there are several types)
- Multiple Pterygium Syndrome

AMC happens when a baby in the womb stops moving for a while. If a baby is not moving about the joints become stiff and sometimes fixed. It is often not possible to find out what caused it. There are many different reasons why a baby might stop moving in the womb, but some of the most common reasons are:

- There wasn't enough room in the womb
- The baby's nerves or muscles were under developed or developed differently
- A virus made the baby or the mother poorly

How common is AMC in the UK?

Why is it so hard to pronounce?

AMC is often described as a rare condition but one baby will be born with AMC in about every 3000 to 5000 births. TAG has over 700 members with AMC but there are many more in the UK who may not have heard about TAG. Some of the conditions that have AMC though are very rare e.g. Multiple Pterygium Syndrome. Meanwhile, the most common type of AMC is Amyoplasia which is sometimes called "Classic" AMC. About one third of all people with AMC have Amyoplasia.

The name Arthrogryposis Multiplex Congenita is difficult to pronounce and very long too. This is because it is describing different parts of the condition:

- Arthrogryposis – 'arthro' means joint and 'gryposis' means curved (in ancient Greek)
- Multiplex – means several
- Congenital – means present at birth

Why does AMC affect different parts of the body?

People are affected very differently by AMC: some in their arms/hands; some just legs/feet; some both; some in their spine and/or jaw too; other parts of the body might also be affected. This is to do with when exactly they stopped moving in the womb and for how long.

In the first twelve weeks that a baby is being formed in the womb the organs are developing. In the 9th week the arms and legs start to form and in the 10th week the hands and feet start to form. So when the baby stops moving at different points of development, different parts of the body will be affected:

- If movement stops at 8 weeks the jaw is more likely to be affected

- If movement stops at 9 weeks – the upper limbs (arms/hands)
- If movement stops at 10 weeks – the upper and lower limbs (arms/hands and legs/feet)
- If movement stops at 11 weeks – the lower limbs (legs/feet)

**Is it permanent or do you grow out of it?
Is there a cure?**

AMC is not something that can be grown out of and so it could be described as permanent. Although with physiotherapy, splinting, and sometimes surgery, the position of the joints can often be changed to make it easier to do things. It is during growth spurts that the joints can become tighter and stiffer so most children and young people with AMC wear splints and will continue to do so at least until they stop growing.

Adults with AMC at the TAG Weekend 2006 said they have learnt to live with their AMC. They do some things differently to other people. To be as independent as possible, some use aids and have had adaptations made to their home – or their car so that they can drive. Some chose to have help to do certain things if they feel doing those things takes up too much time and energy.

AMC affects joints but many would argue that there are other symptoms too, e.g. bags of determination, buckets of personality, a brilliant sense of humour and excellent social skills. It isn't just people with AMC or their parents that say this either! Many doctors and therapists also recognise that people with AMC tend to have more of these qualities than their peers.

These qualities are only too obvious when you see lots of people with AMC together, like at the Annual TAG Weekends or the TAG Camps. But if you can't make it to these events, why not get in touch with TAG office to ask for an updated list of members in your region or to ask how you can have email contact with other TAG members of a similar age to you?

TAG members are real achievers and here's just a few: Paralympic Dressage Multi-gold Medallist Lee Pearson; London Marathon Wheelchair Race Winner Sarah Piercy; world renowned Disability and Education Law Specialist, Human Rights Campaigner & Author David Ruebain

Children with AMC... have a positive attitude and are very determined children who learn quickly and succeed where others might fail...

Dr Gillian McCarthy

Children with AMC are very rewarding to treat because they have the characteristic of being highly motivated and great achievers...

Mr John Fixsen



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