

AMC & Wheeled Mobility Webinar Questions

Dr. Bonita Sawatzky's Answers:

Why do people with AMC have less mobility when they get old? And they say AMC won't get worse when they get older.

AMC is a condition of a variety of causes. The most common type is Amyoplasia, and this has a neurological cause where the cells in the spinal cord (anterior horn cells) are not working as well. These cells naturally deplete in their capability in all people as we age. With Amyoplasia folks are starting at a lower start point so it exaggerates the impact of ageing. These cells send signals to the muscles. If these cells die off, then the cord has a harder time sending signals. Muscles then get weaker.

The weaker spinal cord signals during the fetal development are probably what impacted the joints to make them stiff in the first place. Theories on why these cells had a problem during development are many (disrupted blood supply, viruses (like Zika), other illnesses to mother. Had there been normal signals to the muscles during development, the joints would have moved better and no contractures. Anything that causes the baby to move less during development naturally impacts the muscles and joints. This is why passive stretching early on once the baby is born is so critical and developing habits of being active to keep what you've got working as long as possible. However, one can also push too hard so that muscles get tired and fatigued. Continually fatiguing muscles can cause inflammation and strain. Thus, the concept of conserve to preserve is important. Finding that balance for you is essential.

For other types of AMC, it is not so clear to the cause of the earlier impact of ageing but with any muscle that is weaker to start with, ageing will eventually set in with our decreased muscle fibres. Thus, exercise is so important to develop into a daily habit early on to push off the impact of ageing as long as possible.

How do you describe AMC to people who are ignorant? We just call it "wonky bones syndrome", but I'm sure that could be improved.

See first question's answer.

What is the cause of AMC? Is AMC always genetic? Are there any statistics about AMC in the world? Are there any interested physicians to help AMC patients in Ukraine?

Are there any refugee treatment programs for AMCs from Ukraine? AMC is not always genetic. Most are not but it is important to get a genetic assessment to know what type of AMC a person has. Amyoplasia for example is not genetic. 1/3 of people with AMC have Amyoplasia. There was a group in the Ukraine who were interested in AMC when we first developed the AMC long term study. They asked for our methods for research to do it in the Ukraine. I have not kept in contact since then (Dr Sawatzky).

How will AMC change as my daughter grows? Will the contracture grow with her or will symptoms become more apparent as she grows?

This is really hard to say in this format without knowing your daughter. It really depends on the type of AMC and the limbs affected. Keeping range of motion (the amount you can move your limb) is important with exercise and stretching. Typically, most people with AMC adapt remarkably well. Generically it seems that people's condition plateaus until issues with ageing later in life. This info is not to be used specifically for your daughter's situation.

How do I know when it's time to begin using a wheelchair?

If you are finding that you have no energy to enjoy the pleasures of getting out because all your strength and stamina are used just to survive, then maybe consider a device to get around so that you are participating fully in all the things you want to do. Using a wheelchair for outdoor mobility is totally acceptable! Look at all the people in our world now scooting around on all kinds of devices. They are using mobility devices to get around so why should you not see what works best for you? It does not mean you are a wheelchair user full time. You can still do all the activities you choose to do by walking. Having a mobility device just opens opportunities. Remember to figure out what are your goals for having a device.

I don't have a chair yet but I'm looking to get one because my knees & hips are getting to sore to keep only walking. How do I go about process for help or is there help for this? How do I go about getting a chair?

Every country will have a different process but for most places, the first step is to speak with an occupational therapist or physiotherapist to get started. It is super important to get a trained individual to help you so that you find the best set up for you. Peer advice is also very helpful since many therapists are not so versed in AMC. Do your homework. Check out options prior to talking with someone. Figure out what your goals are for using the device (inside, outside, going to work/school, what environment you'll be trekking over the most, etc.). Make sure you get to try devices in your environment.

Arm bikes (or paraplegic bikes)! They are insanely expensive and need to be special ordered. Also, they aren't made for people with my hands. Is there anyone that adapts them? Offers financing? Does anyone with AMC use arm bikes? My dream is to ride one, but it feels entirely unobtainable. I went to a bike store, and they literally laughed at me for even asking about them.

It may be possible to try one and explored opportunities through a local rehab centre or adaptive exercise program in your community if they have one. Yes, they are expensive and some adaptations like, adaptive hands (a glove) can be used. Specific info for this forum is not possible.

Deciding to use a wheelchair, and the thought process involved in acceptance. I think that Misha's story in the webinar is the best answer for this question. Please review her ideas.

What wheelchairs are in the U.S.?

Please consult an occupational or physical therapist and check online for ideas. There are LOTS of options.

What helped you the most?

I think that Misha's and Kyrby's stories in the webinar is the best answer for this question. Please review their perspective.

What are your future plans on reaching out to people with AMC and health care providers on how wheeled mobility impacts AMC, besides this webinar?

Currently we have no future plans on this topic, but we are always open to new ideas of hope to move things forward. Sessions at the AMCSI meeting are valuable as well if you can attend. It is an American conference, so it is not easy for many to attend. I (Dr Sawatzky) have been hosting the International Seating Symposium in Canada for over 20 years but recently stopped. There is a conference similar in the US, Australia/New Zealand, Ireland, Brazil, etc. where therapists learn about everything to do with seating and

mobility. AMC is not common but many of the principles that are used in seating and mobility apply to all types of people with disabilities.

Kyrby Brown's Answers:

Why do people with AMC have less mobility when they get old? And they say AMC won't get worse when they get older.

It's true that AMC is considered non-degenerative but I have certainly experienced a decline as a head towards aged 30. The decline has been significant in the last 3-4 years particularly. Lifestyle does play a huge part but it's extremely difficult to maintain the line between inflammation causing exercise and health and fitness. Everyone will be different but a holistic approach when looking at the decline is always better.

I don't have a chair yet but I'm looking to get one because my knees & hips are getting to sore to keep only walking. How do I go about process for help or is there help for this? How do I go about getting a chair?

This will be location specific. In the UK the statutory provision of equipment is limiting so I have had to think outside the box with both private and charity funded mobility equipment.

How will AMC change as my daughter grows? Will the contracture grow with her or will symptoms become more apparent as she grows?

This is hard without knowing more. In my experience routine plays a role here and maintaining a good stretching and physio routine will be important. My condition was very stable in my early years and teens and my joints have gotten stiffer in my late twenties. I was involved in sports at school and university which kept me mobile but did cause some wear and tear.

How do you describe AMC to people who are ignorant? We just call it "wonky bones syndrome", but I'm sure that could be improved.

I always explain that my joints are curved and the connective tissues and muscle structures did not form properly. This causes muscle weakness and a restriction in my range of movement. I do a lot of compensating movements and open find unique ways of doing things.

How do I know when it's time to begin using a wheelchair?

This is hard as it'll depend on your individual presentation. I would say that this is a mental challenge as well. If your condition is stopping you from enjoying activities because you're tired or in pain then mobility equipment can help you maintain your quality of life. Using a wheelchair is not a one way road, you can always go back to walking if you want to or need to. It may also be worth considering other equipment. But, if your days are shortened or poor quality because it's hard to get around then a wheelchair may enrich your life more than you think.

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anyone with AMC use arm bikes? My dream is to ride one, but it feels entirely unobtainable. I went to a bike store and they literally laughed at me for even asking about them.

I am not able to use a hand cycle due to upper body limitations myself but I have used power attachments for my chair such as the Triride which is throttle operated and gives a similar feeling. My frame runner has adaptive handlebars and a knee braking system which allows me to be independent. It may be that you need to speak to engineers or local manufacturers about possible adaptations or alternative equipment.

Deciding to use a wheelchair, and the thought process involved/acceptance.

Acceptance from the individual is one thing but this also involves acceptance from the persons family and friends. So often wheelchairs are demonised by society rather than celebrated as a form of independence and a life-enhancing tool. It's important to challenge this mindset where we find it.