

Episode 10: Joint Hypermobility and Autistic Healthcare

Hello and welcome back to Actually Autistic Educator. This is a shorter episode this month because I am still dealing with some health issues, so today we're talking about a common co-occurring condition to autism, generalized joint hypermobility, and some barriers autistics face in accessing medical care.

I've had joint issues of various sorts for years, and last month the root canal was the straw that broke the camel's back, as I've been on some serious mobility limitations since August that spiked to severe pain since mid-December. I'm doing a bit better now, hence being up for writing, recording, and editing a least some, but I'm on a lot of medication and it's still pretty exhausting. Being in physical pain is awful for anyone, but as an autistic because it's a body sensation it also triggers sensory overload for me on top of everything, making it a huge struggle to eat and to focus.

Joint issues are surprisingly common in even young autistics; an article came out just this past month examining the link between autism and generalized joint hypermobility (usually as part of Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder), titled "Joint Hypermobility Links Neurodivergence to Dysautonomia and Pain." In it they found "Neurodivergent participants reported significantly more symptoms of orthostatic intolerance and musculoskeletal skeletal pain than the comparison group," that "there is a strong link between the expression of joint hypermobility, dysautonomia, and pain." and that "Individuals with EDS are reported to be 7.4 times more likely to be autistic than a comparison group." Interestingly, it also found higher rates in people assigned female at birth, which is very consistent with my anecdotal experience. Other articles like "The Relationship between Autism and Ehlers-Danlos Syndromes/Hypermobility Spectrum Disorders" by Casanova et al from 2020 and "The Relationship Between Generalized Joint Hypermobility

and Autism Spectrum Disorder in Adults: A Large, Cross-Sectional, Case Control Comparison" also from February 2022 have also documented this link.

While all of these articles are relatively recent, this link is not at all surprising when you look at what autistic communities have been saying for years - while in theory Ehlers-Danlos Syndrome (EDS) is very rare, approximately 1 in 2000 is a number seen a lot, because I have a very disproportionate number of autistic friends, out of 700 and something Facebook friends I have 8 that I know of for sure who are both autistic and have been formally diagnosed with EDS. Joint pain is incredibly common for autistics, but is almost never included in discussions around accessibility and autism.

On top of the difficulty in getting a diagnosis in general for rare conditions, being autistic can make misdiagnoses much more common. I highly recommend checking out Autistic Science Person's "Autistic Sensory Pain and the Medical Consequences," where they talk about how societal disregard of sensory pain causes serious problems in diagnosis of other medical issues - when your ears hurt from loud noises far worse than your knees do after stairs, but everyone has told you your ear pain isn't valid and you need to ignore it, why would you assume that you should mention other pain?

We've talked extensively in the past about autistic communication differences and the double empathy problem, where non-autistics are shown to be bad at correctly interpreting autistic body language, facial features, and language. This means an autistic who is in severe pain and maybe usually masks but can't and has a flat affect is assumed to be fine because they are not emoting in the ways the doctor expects pain to look like. Likewise, masking has been heavily pressed into many of us, so others may mask and try to "look normal," smiling and following social patterns

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even when in serious pain, making the doctor assume they are fine and this is mild. Likewise pain scales used to evaluate severity are often very broad and rely on vague language that can be misunderstood.

When I was 20 I was having severe back pain, I went to the doctor and he said I needed to walk totally upright across the room. I said if I did that I would be in excruciating pain and I shouldn't. He told me it was necessary for him to diagnose me, so I did it by powering through the agony. He then said if it had really been a serious problem I wouldn't have been willing to do so and told me to take advil and use a heating pad. Turns out I had a chunk of cartilage lodged in my spinal cord that required surgery to remove, and caused lasting damage from the inflammation from leaving it untreated so long. When he said "you have to do this" he didn't mean literally, he was using it as a way to check my discomfort. Others would have probably refused to subject themselves to that pain, but I am very literal and took him at his word because he was supposed to be an authority figure who I should listen to.

Similarly, after that back surgery I was told at a certain point that I should walk as much as I possibly could to regain my strength and speed recovery. I did so, walking as much as I could possibly manage, then woke up paralyzed from the waist down and in severe pain. Turns out they had meant I should walk just until I felt mild discomfort, but many people shy away from pain and so staff didn't expect me to take it literally, and I was in the hospital for 2 days till my back stopped spasming.

Now, I know to check these things. Do you mean walking for 5 minutes every 2-3 hours, work till I hit a failure point or feel mild discomfort? If talking about pain scales I specify what I mean by a number, 8 I couldn't focus enough for work due to constant sharp pain that even my favorite activities couldn't distract me from.

I also often preface things with "I'm super literal

and will follow instructions meticulously, but I have a tendency to power through pain if I'm focused so I need to know what limits I should have." This is all helpful, and I highly recommend using some of these if you are seeking treatment, but it's frustrating that I have permanent damage and a long track record of misdiagnoses just because I took people at their word and answered honestly, and I have seen so many autistics reporting these same issues.

To be clear, I'm not blaming healthcare professionals for these larger blindspots, but we can't fix things if people don't know they are there, and once we know we have a duty to do better.

In general, autistics are more likely to have a wide variety of other health conditions, many that can cause pain of some sort or that require self-reporting of symptoms for diagnosis, making it essential that medical practitioners have a better understanding of autistic communication. According to the 2013 article "Comparison of healthcare experiences in autistic and non-autistic adults" autistics report experiencing significant healthcare disparities. And from the professional perspective the "Healthcare Providers' Experiences with Autism" from 2019 reported that healthcare professionals felt there was a lack of training, knowledge, and resources on how to work with autistics. In fact, an article from 2017 in the UK titled "GPs' confidence in caring for their patients on the autism spectrum" shared that 39.5% of general practitioners said they had received no formal training in autism. And let's be real, for those that did, how much of it was likely conducted from an actually autistic perspective?

Additionally, many healthcare professionals do not listen to AAC users and require them instead to bring a speaking caretaker, even for adult patients who deserve medical privacy. Offices also frequently have other barriers against non-speakers and semi-speakers such as requiring telephone calls to make appointments. I love my orthopedic, and they have a great online system for requesting appointments and

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asking questions, but several times I've ended up having to call in because they admit if they're backed up they don't check it and rely on people calling in if it's important - which also is stressful from a social perspective because I never know if I'm being a good self advocate or I'm going to be treated as an annoyance for contacting them too much.

Oh, and the economic factor is also an issue, for those of us in the US especially who can't afford the astronomical cost of many medical options.

When you factor all this together, it's not at all surprising that autistics struggle with accessing healthcare, especially for support for less common conditions. I'm still waiting to see the geneticist to see if the cause of my current issue is EDS or something else, but the fact that I've had chronic joint issues since I was a teenager, two of which required surgery to treat, and this is only being considered now is rather frustrating. We need better training for healthcare professionals on how to communicate effectively with autistic patients, especially regarding pain, and better awareness of common comorbidities like joint disorders. We also need better accessibility when accessing healthcare with options for non-speakers that don't infantilize.

Related to this but slightly off topic, content warning for brief non-graphic discussion of war. As a reminder with the current attack on Ukraine, the options in case of emergencies are often not accessible to people with mobility limitations, which also includes many autistics as we have just talked about. CNN covered a story, "People with disabilities and mobility issues find themselves trapped in Kyiv" about a family that has both an autistic young person and an older adult with mobility limitations who have been unable to evacuate because of accessibility issues on transport, and likewise cannot access the recommended shelter because the subway tunnel everyone is supposed to stay in is not accessible. If you're able, please consider donating to one of the many humanitarian groups working to assist

refugees and those staying in place during this, the more marginalized a person is the fewer options they likely have in a crisis.

Also, if you work anywhere in the public sphere please, remember to include people with disabilities in any emergency planning, from war to blizzards. For everyone, if a fire alarm goes off in your office or building, what options are there for people unable to take the stairs? Are they listed anywhere? Think if there are things you can do to make your spaces for accessible if something where to happen, like asking about signage or incorporating this information into any safety drills done. There are so many examples of disasters and crises where accessible options in communication and transportation are overlooked and create serious consequences, reminding people to make things more inclusive is so important.

Finally, because we all deserve something to make us smile, I'm adding another famous autistic that you should know about to the list - surreal comedic erotica author and Hugo Award nominee Chuck Tingle. If you've been on social media you have probably seen references to his ridiculously premised books, like "Pounded By The Pound: Turned Gay By The Socioeconomic Implications Of Britain Leaving The European Union" "Bigfoot Pirates Haunt My Balls" and "Pokebutt Go: Pounded By 'Em All", but while it's not a genre I've read much in, following him on Facebook and Twitter has been utterly delightful. He shares his own experiences dealing with chronic pain, explicitly supports LGBTQIA+ people, and is so encouraging of the best parts of humanity, it's just shockingly wholesome and sweet. He is the bisexual autistic icon I didn't realize I needed in my life, but frequently makes me smile.

And on that positive note, thank you all for listening! I may take a break next month depending on how my new meds and PT are going, but I will return in time and finally get back to some of the promised topics with longer episodes. In the meantime, take care, and I'll see you on Twitter and Facebook if you have

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thoughts, ideas, or requests for future episodes.

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People with disabilities and mobility issues find themselves trapped in Kyiv From CNN’s Ivana Kottasova in Kyiv https://www.cnn.com/europe/live-news/ukraine-russia-news-02-26-22/h_5c1d9a3fc12a4aec5b3ed6b0b31bd32

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