

Empowering autistic teens: New clinician advice for navigating chronic pain

February 22 2024



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When you're an autistic teenager living with chronic pain, getting treatment for your pain can be a challenging experience. That's according to a group of young people who've spoken to Dr. Abbie

Jordan of the Department of Psychology and Centre for Pain Research at The University of Bath about their experiences. Teenagers mention sensory issues, a lack of autism awareness among staff, or feeling "doubly different" compared to their peers, making receiving "one-size-fits-all" psychologically focused treatment for their chronic pain particularly challenging.

Improving treatment for autistic adolescents matters because there are widespread reports that [autistic people](#) have shorter life expectancies and poorer health than their non-autistic peers and report receiving lower-quality health care.

Now, her team have come up with a new set of clinical guidelines they hope will make things easier for pain clinicians working with autistic adolescents.

The recommendations, [published](#) in *The Journal of Pediatric Psychology*, include:

1. Provide written / visual information to take home: Consider providing written and/or visual information for the adolescent to take home. Ask about the type of format the autistic individual will find most useful to enable them to follow the information provided. Use pictures and colors if these work for the individual.
2. Ensure that information is individualized: Avoid using a standard form for all adolescents. Include key points and make sure they are pertinent to the adolescent. Adopt language used by the adolescent to answer the questions. Use individualized information to validate the autistic adolescent's experiences and explain how pain and autism may present together.
3. Take your time: If an adolescent has a diagnosis of autism in their [clinical notes](#), plan to go more slowly, take more time with

the clinical work and pause.

4. Include parents and caregivers: Ask and include parents and caregivers; they know their [adolescent](#) best. Shape what the parent / caregiver says outside of the clinic. They can reinforce the clinical work outside of clinical settings.

These recommendations are based on the findings from a study conducted by Dr. Jordan and pain research and clinical colleagues in which they interviewed 10 autistic teenagers and their mothers who had engaged with a pain treatment in a pain clinic. The authors asked the adolescents and their mothers about the adolescents' experiences of living with chronic pain and being autistic.

A mother of a 15-year-old boy with hypermobility spectrum disorder described that for her son, "It's so tiring and exhausting being in pain, and then it's even more so by having autism and then by having it suddenly pointed out that you are so completely different. I think it can be quite isolating."

Regarding psychological treatment for her chronic pain, such as [cognitive-behavioral therapy](#) (CBT) or acceptance and commitment therapy (ACT), 18-year-old "Chloe" said, "Some of the mindfulness ones [activities] are like 'imagine you're up a mountain' and things like that, and I'm just like, I know I'm not up a mountain... I was just thinking, I can't imagine being anywhere other than where I am."

Chloe's mother went on to explain, "The clinicians say, 'imagine that your toes are dipping into the water and how cold it is,' and I can imagine an experience, but Chloe is like 'oh no they're not, so they're not.' So, most of the techniques around anxiety... they're blocked by the ASD [Autism Spectrum Disorder], so Chloe doesn't get the benefit of a drop in anxiety. And therefore, the drop in pain doesn't come because the anxiety threshold is still there."

The teenagers also spoke about how they communicate their chronic pain differently compared with their neurotypical peers. For 15-year-old "Jack," that's by laughing, but it took a few years for this to be picked up by medical staff. His mother explains, "We had a little bit of a problem with physios or doctors not understanding that when he's laughing, he's in pain, so we were almost sort of brushed off, so I think maybe not being taken seriously or understanding quite the level of pain he was in."

It's hoped that the [new guidelines](#) from Dr. Jordan and the team will help clinicians better understand the experiences of autistic adolescents living with chronic pain, and in turn, improve their ability to manage their pain and its impact on their life.

Dr. Jordan explained, "We hope that these simple guidelines will be widely adopted by pain clinicians working with autistic adolescents and that they will enable autistic adolescents living with chronic pain to receive more targeted treatment that better meets the specific needs of autistic adolescents. A one-size-fits-all approach does not work for pain [treatment](#) and that is even more so the case when working with autistic adolescents who live with [chronic pain](#). We hope that these guidelines will encourage the development of more individualized pain treatments."

More information: Abbie Jordan et al, Understanding the impacts of chronic pain on autistic adolescents and effective pain management: a reflexive thematic analysis adolescent–maternal dyadic study, *Journal of Pediatric Psychology* (2024). [DOI: 10.1093/jpepsy/jsae004](https://doi.org/10.1093/jpepsy/jsae004)

Provided by University of Bath

Citation: Empowering autistic teens: New clinician advice for navigating chronic pain (2024, February 22) retrieved 27 April 2024 from

<https://medicalxpress.com/news/2024-02-empowering-autistic-teens-clinician-advice.html>

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