

## **Paul Evans**

This is *Airing Pain Supplement*, brought to you by Pain Concern, the UK charity providing information and support for those of us living with pain, our family and supporters, and the healthcare professionals who care for us. I'm Paul Evans.

Edition number 91 of Pain Concern's *Pain Matters* magazine will be released on 3<sup>rd</sup> March 2026. It's guest-edited by the Bath Centre for Pain Services Co-Production Team. It focuses on neurodiversity, shining a light on underrepresented challenges and harmful misconceptions, and how every patient is different and needs to be treated, and appreciated, as such.

As an *Airing Pain* podcast supplement to this important edition, I spoke to Dr Dave Moore, Reader in Pain Psychology at Liverpool John Moores University, who's researching the pain experiences of neurodivergent, primarily autistic, people. He is himself neurodivergent. So do neurodivergent people experience pain differently to those who are neurotypical?

## **David Moore**

That's one of those questions that kind of has a simple answer and a more complicated one. The simple answer is no, they don't. If we bring neurodivergent people into a lab and do pain psychophysics to look at pain thresholds, then thresholds for a neurodivergent population do not seem to systematically differ between a neurodivergent population and a neurotypical population. The slightly more complicated answer is there do seem to be more people within the neurodivergent community who might feel pain slightly differently, so there might be more likelihood of having someone who responds to things a little bit more differently, even if the population overall doesn't differ. And beyond that, things like anxiety around pain, anxiety around approaching healthcare situations, are more prevalent within neurodivergent people. And for that reason, if you've got somebody who's hurt themselves and is in A&E, they may well be feeling that in a different way to their neurotypical counterparts sat opposite them who've done the exact same injury.

## **Paul Evans**

So as far as measuring the pain, the pain might be the same, but the reaction to it is different.

## **David Moore**

Quite possibly, yes. I think there are lots of different ways that might differ, both in terms of the intensity of that pain that's reported, but also in terms of how that's communicated to other people. And that might be a very high level of distress in somebody who's incredibly anxious. But it also might bring in challenges and issues around things like shutdowns and other kinds of issues where a person might actually almost appear catatonic and as though they're not in pain at all.

I think there's always that challenge that we have to acknowledge when we're thinking about how I communicate my pain to you. Any social communication we have has that

social value. I'm trying to share my state with you, and the reason I would share my state with you is because I think you can help me. And if for some reason I don't trust you, I don't think you can help me, then I might mask that pain. I might hide that pain, I might camouflage it. And we think that might be more common within a neurodivergent population. It's possible that somebody might be in a considerable amount of pain, but might find the social context so challenging that they may be masking those behaviours. So it's a really complex picture.

The work that we did early on was much more in that, what are the pain thresholds in autistic people? And are there fundamental differences in the way that the autistic population feel pain? We could keep doing that for probably forty years, but I'm not sure that we'd learn a huge amount more at the moment.

And the need that we have is that autistic people are overrepresented in chronic pain services. About two to three percent of the population are probably autistic, once you correct for underdiagnosis. About a quarter to a third of young people accessing chronic pain services and the most complex level of care appear to be autistic and more widely neurodivergent.

So we've got a huge number of autistic people in pain services. And I think that raises two questions. One is when people are in those tertiary pain services, what can we do to remove barriers to accessing healthcare and to improve the outcomes from multidisciplinary pain management services? The other is why is it that neurodivergent people are passing through our primary and secondary healthcare systems and are going on to have acute pain become chronic? So those are really the two questions we're trying to address at the moment, is how can we best treat pain and how can we best support acute pain to stop it becoming chronic?

### **Paul Evans**

Okay. Let's start with the first one. How should, how could, somebody with chronic pain who's autistic or neurodivergent be treated.

### **David Moore**

So the first thing is that the treatments that we have appear to be broadly effective. So I would say that if it's a young person, in particular, who is presenting as neurodivergent and has chronic pain and is going for a tertiary pain service, then they will probably respond to that combination of pharmacological management, physiotherapy, talking therapies and more general, you know, family support.

But there do seem to be some barriers in there. Our pain management approaches use a lot of imposed metaphor. There's a story that's often told about, imagine that we're on a bus and the bus is going where we want it to go, and then another person gets on and that person's called pain, and they want the bus to go somewhere else. And then fatigue gets on

and it wants... We've had a few of our autistic patient partners and participants say, I'm not on a bus, I'm in a pain service, and I can't imagine not being in a hospital at the moment.

### **Paul Evans**

So in a clinical situation, somebody who has autism and has chronic pain, the clinician who's been on all the courses is listening very carefully. He moves forward slightly and he's nodding all the places. Yes, I understand, I really understand what you're going through. Showing empathy, if you like. That comes across completely differently to the patient.

### **David Moore**

It certainly has the potential to come across very differently. It may be that for somebody a very direct kind of eye contact may be actually quite confrontational and may feel like they're being judged. Even a sentence like 'I completely understand what you feel' is a really common way that we often share our conversations with people. But the reality is, you don't know how that person feels. You neither have their neurotype nor do you have their chronic pain condition. Again, for a lot of neurodivergent people, communication can become kind of slowed in certain conversations, or people may be very deliberate over words that they pick. And it's very tempting for a neurotypical person to fill in the words that they are expecting to continue that kind of communication going forward. But that can really invalidate that experience, and giving people just that space to end their own stories or to complete their own narrative. All of these kinds of small things can be challenging.

There's a really interesting model that we try and keep in our mind with a lot of the work, really all of the work, that we're doing at the moment. It's a model that's quite old now, but it started to pick up a lot of interest in our service. It was developed by a guy called Damian Milton and it's called the double empathy problem. Essentially, it was a counterpoint to the idea that autistic people don't have empathy. The idea here was that people empathised, but empathy is a set of behaviours more than anything else. If you don't empathise in the way that the person you're talking to receives, then you'll perceive that person to be unempathetic.

Now, the majority of people are neurotypical, so we have a shared way of communicating, of sharing our experiences, and we get to feel like we know each other quite well. If we're working with somebody who's neurodivergent, by definition that's somebody who has a brain that works in a different way. And because of that, what we find is that if you put two neurodivergent people together, they empathise really well with each other. They have a shared understanding, a shared kind of world. A part of the challenge of this double empathy problem is that you're trying to build a relationship across neurotypes. You're trying to have a situation where a neurotypical and neurodivergent person are trying to share their spaces.

An example I would always think of is, if you travel to somewhere in Asia with a very different culture or somewhere in Africa with a very different culture, it may be that you can even learn some of the language, or you can find a common language, you can talk, you

can understand, but really understanding the culture and the experiences of that person, where their life is so different to the way that you see it, is a much greater challenge. And the double empathy problem, I think, is not too dissimilar to that. You're trying to understand somebody who doesn't view the world, and from the day they were born didn't view the world, exactly the way that you do or did. It takes a real amount of stepping back and just seeing how is it that I can try and, if not share the space with this person, allow them to try and share their space with me.

I think a part of the challenge is that our best way of managing pain, generally, certainly at scale, is by group treatment. So you may be finding that you're treating, let's say, eight people, two of whom are neurodivergent, one of whom may also be currently undiagnosed. Especially for neurodivergent young women or gender-diverse populations, they often receive their diagnosis later and have other complex walkways through that journey. So there's the possibility that the provider either doesn't know, or that the general feedback they're getting is positive. And beyond that, the social anxiety that's very common within neurodivergent and particularly autistic young people, to go to somebody in a position of authority and say, 'This isn't working for me' is probably not there. So I think one of the challenges is that for a lot of healthcare providers, they probably don't realise that they're losing their neurodivergent patients along the way, because no one's feeding back to them that 'This metaphor is not working for me'.

### **Paul Evans**

So how do you get that over to the profession?

### **David Moore**

One of the big things that our lab's saying, whenever we're invited to speak to healthcare providers now, is if you're treating people in pain, you're treating autistic people in pain. The reason that your service is possibly not getting the figures that get you extra funding from the government, or that you're sitting in meetings and trying to work out why you're discharging patients who are not recovering, is that you've got neurodivergent people in your service who are struggling with the treatment you're providing. And if you make some small modifications to that treatment, if you're culturally sensitive in the way that you deal with those young people or those adults as well, then we might just find that we get the double benefit, that there are fewer people suffering, fewer people coming back who need to be treated again. And our services are getting better outcomes, and we can kind of say that we are improving the pain experiences of our patients.

### **Paul Evans**

That's Doctor Dave Moore, Reader in Pain Psychology at Liverpool John Moores University. *Pain Matters*, guest-edited by the Bath Centre for Pain Services Co-Production Team, will be available on 3<sup>rd</sup> March 2026. Check out the Pain Concern website at [painconcern.org.uk](http://painconcern.org.uk) for more details.