



# Interview with Katie Hall

During autism awareness month we wanted to make sure autistic people within our community were able to have their say.

We spoke to **Katie**, an autistic mother to two autistic children about her experiences.



**Q: What does autism mean for you and your children?**

A: Well for me I think it's like a super power. Particularly with the children, because I'm hoping that they're going to grow up and develop in a world where autism is more accepted, or neurodiversity is more acknowledged and accepted and embraced. So, where my son may lack in some areas, on developmental delays, he absolutely smashes it in other areas. He's an engineer in the making.



**Q: How does autism affect the way you and your children see and interact with the world?**

A: To have that ability to look and reflect on things from different angles to what a neurotypical person would see is, to me, it is like a superpower. I do think people underestimate autistic potential. It's one of the biggest mistakes society continues to make - autistic people are game changers because we're alternative thinkers.

I know lot of parents out there that don't understand autism, and when it's mentioned to them that "your child could be autistic" I don't think they really appreciate that this is quite a special thing you have going on here. You can just see in this little person that they've got this huge potential, and whatever they set out to do or find an interest in, they will just, yeah the potential in that and just the passion for what they enjoy doing is phenomenal.

I can see that with my son. He will just take Lego, and it'll be from all different sets and he will suddenly build a street scene that's got a fully functioning lorry in it, and you know traffic lights and the works! You're just like, where did that come from!? In yourself, things that you are good at just make sense.



### Q: What sensory differences do you and your children experience?

A: Everyone has sensory issues. People just think of the basic senses, but then on top of that you've got proprioception\* and interoception\*, which is something that even a lot of teaching staff and all the rest of it will not understand. I know personally with my experience with my son, who wasn't continent, I had to explain to school about his interoception system - so that's the sense of thirst, hunger, toileting. My son was needing to wear continence aids in school and it was sort of like 'stop pushing it', because if that sense hasn't developed you're just berating him for not being able to get something, when he just hasn't developed yet. Because he's just developing at his own pace.

One of the things I struggle with is, if you're in a restaurant and you're trying to have a conversation with somebody with a lot of other conversations going on, I can't hear you. All I can hear is whatever conversations are going on around me - I can't focus on you. I actually wear earplugs which help with that, and it muffles out a lot of the sound, and I can then focus on the conversation I'm having with you.



### Q: What do meltdowns and shutdowns feel like?

A: An analogy I use with the kids is the Coke can effect - that each little thing is a shake of a can. Say you get into school and the teacher isn't the normal teacher, it's a substitute teacher - that's a shake. Someone knocks you in the corridor - that's a shake. I haven't slept well, so that's a shake. You get up, you find a dead mouse on your carpet - that's a shake. You get to school and you're late - that's a shake. You think you've lost your phone - that's a shake. It's that constant shaking, so you get to a point where that inside cannot take any more. If you then were to open that can, that fizzy drink is just going to explode everywhere. And that's the feeling of a meltdown.

I don't have very many meltdowns - they do come occasionally, and it's a lot of crying, a lot of snot. I tend to have more shutdowns. For me a shutdown is I just feel like I can't continue adulting, parenting, being a human being right now. I just want to go and find a little dark corner, and I just want to have nothing, just nothingness. I could be like that for 5 or 10 minutes, or I could be like that for hours - then I'll just suddenly feel like "phew, that's better". I know when one's building, because the pressure cooker inside is building, and you need to basically pull the release valve. I just go very, very quiet, and want quiet. But then that recharges me, and then I'm all good again.

**\*Proprioception** is the sense of self-movement, force, and body position - like knowing your own strength or whether you're standing on a soft or hard surface without looking.

**\*Interoception** is understanding the internal signals from your body, like when you are hungry or when you need the toilet.

You can see the signs, I mean, when you know your kids, when you know yourself, you can see the signs of a meltdown building up. And you're just thinking "do I need to be here? Or can we get out now and go and find a quiet place". And sometimes I'm like "no, we're going to have to have a big old glass of suck-it-up juice and just get on with it", because we don't have a choice. But we're like "just stick a pin in it. We can still have this meltdown, we just can't have it now". What we'll do is, when we're away from this, we'll go and have a nice scream or whatever we want to do, and process that feeling, that emotion, that energy, but right now we can't do that. I'm teaching the kids, because you have to fit in to this neurotypical world. Well, that's how it feels as an autistic person, that you have to make permanent accommodations so you fit in and don't cause any stress for anyone.



**Q: What is masking, and why do you feel you have to do it?**

A: Up until a few years ago, when I got a diagnosis, I thought that was normal. I thought you put on a brave face, put on this bravado. Masking for me was just everyday – particularly in childhood, there wasn't really a safe space, so masking was just permanent.

I'd sometimes be really anxious about going to work, because of something that was coming up that I'd really struggled with. And I might be a crying wreck, and then I'd kind of just get it all together, and go into work, and then be like "oh yes, you can see the Katie that's got it all together", where in actual fact underneath that I'm like "no, I think I want to go and have an anxiety cry in the toilet while no one's looking". And I would need medication to help me with the anxiety. Up until I got my diagnosis, I thought that was normal. I thought that's what everyone else was going through.

Depending on what you're doing, depends on how thick or how big the mask is. It could be like a small cartoon mask, and that's you just nipping to the shop to get something. Or something more serious, you've got to go see the tax office about something, and that's going to be a whopper, that's like a big, full on welder's mask. That's how it feels to me – like you're putting on a persona that you think fits with the situation or environment you're going into.

It can be detrimental to work, or your school environment, because you're putting in so much energy, mental energy, mental load, in being what you think other people want you to be. If you could put that focus onto your work, then just imagine the potential.



**Q: It is useful to think of autism as a high-low functioning spectrum?**

A: I think that's a really antiquated idea. Most people's perception of autism, I think, is either you're really complex needs, and you may be non-verbal, or you've got significant learning development delays, and you might have global delays. And then on the flip-side, they think someone who is 'high-functioning' is someone who is literally like a computer, like Rain Man.

There's a really hot debate in the autistic community – I prefer personally to be called an autistic person, or a neurodiverse person, whereas technically I have the label of Asperger's, which is a really out-dated label. My daughter has the same label, and my son has the label of classical autism. But autism isn't linear, it's very much like a circle, and you have your areas of strength. Some areas you will really excel in, and some areas you won't. And then each day will be different – so one day your executive function might be low, but then today you're having a good day and it's bigger, there's more of it. It's ever evolving, ever changing. This higher-lower functioning thing, it really needs to be put out there that that's just not the case.

You can have a child and their social skills may be reduced, their sensory issues might be really big, and their executive function might be really low, but because their fixation is really high they're able to really hyperfocus in on their area of interest and be really excelling at that. To me, that person's high-functioning in that area.

I prefer, where NICE guidelines have got to – we should be calling it an autism spectrum condition, because it's not a disorder, there's nothing wrong with us, we've just got a different neurotype. Our brain is built differently to yours, and that's what needs to be understood more in society.



**Q: Do you think there's less understanding of autism in women and girls?**

A: Yes. All the autism questionnaires are still based on the male profile of autism. It may be different and it may be changing within the UK, but the current guidelines for questionnaires are all based on a male diagnosis, and it's different. On the whole, female presentation is different. Because girls are trying harder to fit in, because that is the social side of being female.

Particularly in school, you're trying to fit in, you're trying to develop friendships. And I can see the differences in my two children – my son isn't bothered that he doesn't have a particular set friendship group, it doesn't bother him in the slightest. My daughter will have so many struggles, because she can't understand the dynamic of the girl group she's in, and will come home every day and there'll be another issue. That understanding and those social connections are just expected of girls – you're expected to be a social butterfly, and understand the situation, and have all these lovely friends.



**Q: What misconceptions about autism would you like to remove?**

A: I have a very dark, dirty sense of humour. And it's assumed that, because I'm autistic I can't have a sense of humour, I can't love sarcasm. But there are so many autistic comics out there, and people don't assume that, because there's a stereotype that you can't have a sense of humour, you can't understand sarcasm. That stereotype is so frustrating.

“You don't look autistic” is the phrase I hate so much. For me, it makes me feel like when you get your autism diagnosis they go out and get a hot-iron and

brand it to your forehead that you're autistic. So without having that on your forehead, you couldn't possibly be autistic. But there isn't a specific look and we don't get up in the morning and put on a label that says "Hi, my name's Katie and I'm autistic". It really is damaging, saying that, because it's making out that what you've gone through, the journey you've gone through to get there is just completely dismissed.

Or "everyone is a bit autistic" – honestly, it just makes me see red when someone says that. I think, in their way, they don't know what to say – I think they're trying to put you at ease, where in actual fact they're really, really annoying you by saying "well, everyone's a little bit autistic". No, they're not. You can be neurotypical and have a day where you're a bit more sensitive to noise, and you just feel what we're feeling a bit more than you would normally. And yeah, neurotypical people with anxiety will mask in certain situations, or put protective barriers up because that's a coping mechanism, but that's not their life, that's not their everyday – that's just their coping mechanism in that time-period. By saying that everyone's a little bit autistic, it's so derogatory. I'm going to speak for the autistic community – we'd like that to stop, please. And also, if someone could tell me what an autistic person is supposed to look like, that would be great.