

Autism: Masking, Diagnosis & Mental Health (With Alex & Alex's Dog Buddy)

Romy: Hi everyone, today I am talking to my very good friend Alex and we are going to be talking about autism and mental health.

Alex: Yes, so autistic people are predisposed to mental health issues like anxiety, depression and other comorbid things like OCD, ADHD, and Tourette's. I guess starting off we kind of have a bad hand, does that make sense?

Romy: Yeah, we are more likely in the first place to develop conditions, because autism often does come with other things.

Alex: Probably because of how the brain is wired. When I was younger, before my mental illnesses started, I was already quite a shy person and kind of scared of rejection because throughout (as a kid), because I didn't know social rules I was just hesitant. I was quite naive and I was very trusting. I still am, which is not always a good thing. I think that was some of the basis of why I developed mental health issues, because of having those struggles with autism as a child and not knowing why.

Romy: Do you think that your self-esteem was impacted by not knowing why you were different?

Alex: Yeah, I just felt like I was doing things wrong, I kind of felt like I was dumb. I was like "Everyone else seems to be doing fine, why can't I do this?"

Romy: I feel like unfortunately, that's a feeling that a lot of people with neurodivergent conditions get (autism, ADHD, etc.), because people hold themselves to neurotypical standards, especially if they don't know they have a condition, because they feel like that's what they're supposed to do, but of course it's difficult when your brain is working very differently.

Alex: Yeah, and I think parents, if they don't know or don't think that their child has struggles then they invalidate it a lot, and that can be really negative on the child's mental health even if the parent doesn't mean it to be that way, they just want their child to act normal - "Just don't embarrass me." That's what they want them to do, but it's harder when you have a neurodiverse brain.

Romy: I think because things like autism can be very hidden sometimes (from the outside anyway), people might not feel that it's worth looking into, like parents, because they don't see what's going on inside, and I think some parents do worry about...

Alex: Labelling.

Romy: Yeah, labelling. But there's a thing I've seen loads of times - you're going to get another label that's a lot worse, people being bullied and called horrible things, and that's a lot worse label for someone to have and harms someone's self-esteem more than knowing they're autistic, because there's nothing actually wrong with being autistic.

Alex: Yeah, because my mum said that she did have some concerns but she didn't want to take me to the doctor because she didn't want me to be diagnosed and also, one of my mum's friends who had a baby at the same time, he was doing the same things as me, and I think he's autistic as well, because we were both doing the same kinds of autistic things - repeatedly opening doors and all of that, but they were like "Oh, that's just normal!" It was just a mixture of not wanting to label and not thinking it was a problem, and I know that I was quite good at masking when I was a kid. I kind of masked naturally because you know "Everyone else is doing this, so that's how I've got to do it," and I remember being told social rules when I was about five or six by the teacher, like "You need to look at someone when they're talking to you," so that's what I do now. I think in childhood before you get diagnosed, that's the general feeling.

Romy: Yeah, I've heard it is very common for some people to mask, autistic girls especially, and that masking - it's not always a good thing. Some people might think that it is a good thing, because maybe it makes us seem like we are functioning more, but it actually can have negative effects because we are masking our own feelings as well.

Alex: Like pushing down feelings and sensations, and it can make you burn out. You feel really tired after school, you need to go away and be by yourself because you can't deal with people because it's just too much. Personally, masking affected my schoolwork a lot. If I was having a bad day and I was trying so hard to keep up the neurotypical front, I could barely

get any work done because it was so draining. It is not good to mask, but it's ingrained into you as a child to do that because neurotypicals want you to act like that - and it's not against them, it's not their fault, it's just hard.

Romy: And I think people probably don't see how draining it can be to be autistic, especially if you're not accepting yourself that you're autistic. Do you think your mental health's improved in any way since getting a diagnosis?

Alex: Yeah, definitely. I've been a lot kinder to myself. When I started researching autism, I was like "Wow that actually makes sense, I could be that." I was scared because I thought people were going to judge me and be like "You're not autistic," and they were, and they did say that. But I guess I proved it by collecting situations, which showed I was autistic, like memories and timeline of my development.

Romy: When people say "You don't look autistic," it's quite difficult because you don't need to prove yourself to anyone but you kind of feel like you want to. In a way you want people to believe you and take you seriously.

Alex: You want to validate your feelings, because people think that you haven't got it that bad, because you can function in an environment, but it can be really taxing on your brain so you kind of want to be able to prove to someone "Yeah, I have these problems and they're valid, and they make me feel bad."

Romy: I did notice when you were diagnosed you started actually stimming more and being outwardly autistic and I think that's actually a good thing. I was really happy when I saw you stimming!

Alex: I didn't really stim that much as a child. I'm not sure why. I think that staring (because I was zoning out constantly as a kid), I think that was a kind of visual stimming, because I would watch an object and completely block everything out. I kind of felt self-conscious because I wasn't rocking as a child, why am I rocking now? But it's because I'm comfortable with it, letting out my energy instead of keeping it inside and being restless and anxious.

Romy: It does really help to stim and be able to let it out. I do rock a lot (for some reason I'm not actually doing it right now I think), and I do jump up and down and wave my hands. If I didn't do that I'd probably be a lot more miserable, because it does release a lot of energy, and stimming does actually feel good, it kind of serves a purpose, so I'm grateful that I have been able to openly stim without judgement.

Alex: I guess in school I do it in socially acceptable ways like knee moving, chewing a pencil, or tapping, which might have been kind of annoying for people around me but I don't care. I would get it out that way, it's nice to do stuff that feels natural.

Romy: Definitely. When I need to rock and I don't rock it just feels weird, so it's definitely better to do what naturally comes to you.

Alex: The same when I'm excited about something [demonstrates shaking arms and hands], "Yay, oh my gosh," because of so many feelings. I did also do that before I was diagnosed, pacing around [shakes arms], because of intense feelings about ideas, and it's really fun.

Romy: It is very fun, I do that as well!

Alex: But it's not fun for the parents who have to listen at like 11pm or 12 at night. They're like "Let me sleep."

Romy: What do you think is the danger of suppressing your feelings as an autistic person, that might bubble up?

Alex: I guess it can show itself in a lot of ways. Some people get really angry and lash out at people. Other people take it in on themselves - they build up a lot of anger and hatred about themselves, like "Why are you like this?" So that's the danger of keeping it inside, and also burning out from masking. Yeah, that's the danger.

Romy: Have you ever had a doctor or a therapist say they don't think you're autistic?

Alex: Surprisingly no, because I was the one who brought it up to them. When I was about 12... is it the psychiatrists who do the medication?

Romy: Yes.

Alex: I had a psychiatrist who asked my mum some questions about autism and she's like "no no no, she's not autistic," and that was that, but then at 14 that's when I started researching it and then I brought it up to my therapist and she was like "Yeah, I actually thought you might be," and I was like "Why didn't you say anything?" So surprisingly no, but I guess it's because I was scared of people telling me.

Romy: I think advocating for yourself is really important and researching it yourself does help a lot.

Alex: Yeah, I threw myself into research before I even mentioned it because I did not want to be wrong, because autism is like...

Romy: Complex.

Alex: Yeah, it's really complicated. It's your brain, I feel if you get it wrong it would be insulting to autistic people. So I researched loads, I made loads of notes (like four pages of notes), I went to my therapist and was like [mimics putting papers on a desk], "I think I'm autistic."

Romy: Oh wow!

Alex: And she was like "Yes, me too - I'm going to help you," which was nice, because she was a nice person [puts hands together in prayer gesture]. She's not dead, she's still alive. She IS a nice person - I just don't see her anymore!

Romy: That's really nice that they were really open to it and everything, that's lovely.

Alex: It's confusing, because other people have different experiences with CAMS so it really depends on the person you're seeing.

Romy: Yeah, I think that as well. So, what would you say to the parent of a child who is maybe showing some potential autism traits like sensory issues, literal thinking, etc.?

Alex: I would say write down your thoughts and memories and worries, to compile it together in a comprehensive list. Obviously do research, and then if you think that it's enough then you could go to the GP and say something about it, because it's better for the child to know they're autistic than think there's something wrong with them and blame it on themselves.

Romy: I agree with that, I think it's good to make notes of the symptoms or the traits, so that you can bring them up.

Alex: And have something to say.

Romy: Yeah, and try not to be reluctant to do it. We already kind of said this but, some people feel there's a stigma around autism, but it is better to know you're autistic than to think you're a bad person or that you're flawed in any way. Would you say that your autism impacted your OCD traits?

Alex: I guess people with autism are predisposed to OCD in the first place, because we like routine, we're quite black and white thinking and then obviously anxiety, so I think that boiled over into my OCD episode. I guess the black and white thinking was like "If you don't do this, this bad thing will happen," and there's no in-between. So, I think that kind of affected it that way.

Romy: I think the overlap is black and white thinking and literal thinking can kind of be in both autism and OCD, but with autism it's more generalised and with OCD it's more black and white in relation to obsessions, if that makes sense [Alex's dog Buddy licks Alex's face]. Hi Buddy!

Alex: I guess I... [Buddy stretches out in front of the camera] Bud!

Romy: [Laughs, claps hands] Hello! You want to be in the spotlight, don't you?

Alex: You want some attention, yeah? There you go [Alex and Romy start petting Buddy].

Romy: I don't even want to edit this bit out.

Alex: Yeah, we can just have a little dog segment.

Romy: Love it! Aww Bud [pets Buddy].

Alex: He's like "Yes I'm here too!" I don't have any food for you, you can't eat nuts [Buddy sits in front of the camera, Romy laughs]. Um, you can't really sit there.

Hi, I can still see the camera I guess. He could just stay here for the rest of the video...

Romy: I mean, I could move over a bit and then...
[laughs] aww Bud.

Alex: [To Buddy] You wanna sit over here please?
[Buddy gets up] Thank you [Buddy shows bottom to camera]. Oh, yep, just showing yourself off, that's very nice!

[Romy laughs, claps]