

The Autistic Life Podcast

EP04 Transcript

Host (00:43):

Welcome to The Autistic Life podcast. This is episode four and yeah, I finally feel comfortable enough to start recording again, for those of you who don't know me or have just started listening to me or don't follow me or whatever. I started my second year of college last month. Yay. I'm studying to become a licensed psychologist, which is my special interests, so double yay. But that meant an avalanche of changes that I was so not ready to deal with. I'm okay now. I'm sort of. I'm slowly finding a workflow that feels comfortable for me. Although I fear that the second I start to get comfortable with my new routine, it will change again. So, yeah. Anyway, I'm rambling now, and this whole thing is actually what inspired this episode. So let's get into it first and foremost. Thank you so much to Tiimo for sponsoring this podcast.

Host (02:01):

If you don't know, Tiimo is a paid subscription app that helps you organize your life. It can help you create routines, checklists and keep up with everything that's happening in your life. And it's literally the tool that has kept me afloat during this very, very unfamiliar times. If that's something that you are interested in or feel like you like to, I don't know, give it a try, please head over to tiimoapp.com or you can just click on my show notes and you'll find more information about them. And before we start as always a quick disclaimer, this is my understanding of things. This is a result of like a combination of my lived experience and research and talking to other autistic people, plus my

understanding of things. So you are a hundred percent welcome to disagree with me, or don't relate to my experiences.

Host (03:11):

That's fine. They may be entirely different from yours and that's fine. It's all good. The important thing here is that nothing is fixed. So please just take what resonates with you and if anything resonates with you and just leave the rest. Okay. So that's, it let's jump right into the episode.

Host (03:38):

So changes, transitions, novelty... If you are autistic yourself or if you, if your loved one is autistic or both you are probably familiar with the fact that most of us, most of us don't like changes. And personally I hate them. I hate changes. And even though logically, sometimes changes are necessary and they bring so many good things. It's the in-between that it's, it gets very, very scary and overwhelming. And I've been, yeah, I've found myself needing to change things and knowing that I need to change things and actually being a hundred percent confident that the change must be done and I've felt scared as well.

Host (04:47):

Like it's just like, it's something that is beyond yeah, logical sense, because I feel like many of us when we have to face change, not like an abrupt change, right? But something that, you know, that it's planned, I feel like logically we know that sometimes it's just, we can't control it or sometimes it's a good thing, but it doesn't mean that it's not scary. And I really want to talk about that. Like, why is it scary for many of us? Why is it overwhelming? Why, why do we sometimes have these... we manifest all of these huge emotions and scary

emotions through a meltdown or a shutdown because of changes. So I really wanted to talk about that.

Host (05:49):

As autistic people, we live and experience the world in a way that it's like... if we were a house, like all the windows are open and all the doors are open and we just, we have no control of what comes in and comes out.

Host (06:14):

So when we know what's going to happen, we, we know how to prepare ourselves and we know what will or might, or there's a very good chance that will come in and what will come out. And personally, that makes it way easier to manage, because the thing about changes is that changes leave so much space for so many new possibilities. So ,for example, if I plan to do something and the thing doesn't happen, and I planned it in a way I have ensured my safety, I know that I'll be sensory comfortable. I know that I'll be emotionally comfortable, like I know that I'll be having a good time and when something, an element of that scenario changes for whatever reason and I am not even the time to process it and integrate the change is just it opens up like a whole new array of possibilities. And it gets even trickier when we can't put a pause on it or we aren't allowed to just process whatever's happening.

Host (07:45):

So, yeah, changes are very scary, especially because as I said, it opens up a whole new array of possibilities, and many of those possibilities could be good and great and wonderful, but they could also be terrifying and horrible and uncomfortable. So, yeah, it's, it's not easy. And I feel like when changes are a bit

more prolonged, if that makes sense, like, for example, in my case starting college is something that, it just, it changed everything. And for a long period of time, because until this semester is over, I'm stuck with these changes, which I feel like it's a different reaction than when it's a one-time thing. I'm not saying it's, it's, it's easier or harder. It's just, I feel like it's different. Like when I, when I have planned something and for whatever reason it doesn't happen or something about it changes I feel very stressed out and I feel very overwhelmed. And I get like a knee-jerk reaction of just saying, no, like, "no, I don't want to be a part of this anymore, because I said, yes under certain circumstances and those circumstances aren't happening right now so I don't want this." Whereas when it's long-term like in this case you have to do the thing (anyway). like, in my case, go to college while you are experiencing all of this overwhelm and it can be very challenging and it feels like you can't put a pause on it. So even though you are feeling overwhelmed and stressed out and you just want to scream so the world stops functioning for a while, so you can catch up it just... It doesn't happen. It's not like you can remove yourself from the situation because removing yourself from the situation would mean that you would have to drop out of college

Host (10:04):

Which has been the case for me. And I know it is the reality for many of us. We end up dropping out of college because we just don't have enough support to get through it because it's, it's really... I feel like it's yet another thing that a lot of neurotypical people, and non-non-Autistic people actually, just don't understand, because how do you explain to someone that a change is scary? Like or, that if someone says, "yeah, I know it's scary, but just get over it." And it doesn't help. Like, it's hard to explain without sounding like you are making up

an excuse or that you are just "overreacting." But the fact is that they are scary because it means new scenarios and it means new elements playing a part in your life. And it means new people. And it's just, and it means new ways of acting.

Host (11:18):

And for many of us that unpacks so much, because it means, for example, in a setting such as college or work, if you start a new job it means that you need to get to know the grounds, like, "okay I'm going to need to mask, how much am I going to need to... like for how long? Can I tell people that I'm Autistic? Can I tell people that I need more time to do X, Y, and Z? Do I feel safe to tell them? What are they expecting of me? It's just, there are so many questions happening that, yeah, it's just, it feels so much safer to just stay on familiar grounds.

Host (12:14):

Many of us have such a hard time adjusting to new environments and new people and new sensations and new voices and demands and expectations. And there's, there's so much going on that it takes awhile for us to feel safe. And once we do, we feel safe with people or in a place, it's really hard to give that up. If it works and I'm comfortable with it and I feel okay with it, I don't want to change it. I don't understand why I would change it. And I know that my psychologist would say, "Whoa, but you don't know if it could get better." And, yeah, that's true. It could get better if I, if I would change things, it doesn't mean that maybe I wouldn't enjoy the new thing, but I don't always feel brave enough to do it. And I don't always feel interested enough in that possibility to do it. So yeah, I just stick with what feels okay. And with what I already know that feels okay and safe and comfortable and something that I like.

Host (13:43):

For me a familiar place or a familiar routine or group dynamic, for example it means that it's also a familiar degree of stress, if that makes sense. Like, I know that, for example, during my, my Zoom classes, I, I know what to expect. I know how bad it can get when it comes to sensory input. I know how, how much I have to mask. I know most of my classmates already, because I, because of last year and it doesn't mean that it isn't scary because it is so, so scary for me... like a large group of people is just like AHHGRR but it's a familiar kind of scary, it's something that I know that I have been able to deal with in the past. And I, I know I can deal with this and I have enough resources and support to handle that kind of stress.

Host (14:59):

But if something changes, like something big changes, for example, let's say that you just, you put me in an entirely different class and I don't know any of the people there is just, it starts to be, yeah, it's a... I don't even want to think about it. I'm feeling already overwhelmed like by the idea of it, of having to meet new people and just like telling everyone that you're Autistic and this and this, nooo. It's just the idea... Only the idea is enough to, to put me on edge precisely because of how, how scary changes are.

Host (15:47):

Another thing about changes is that, or unfamiliar places, is that many of us rely on a lot of scripting and a lot of masking to be able to kind of feel comfortable around people and socializing. So not knowing who will be there or thinking that someone will be there that, you know and you feel comfortable

with and it turns out that they weren't going to be there. It just, it leaves space for so many uncomfortable and awkward social interactions. And that alone can be so stressful. For many of us, I include myself in this... Well, you are probably listening to this and "like, Oh my God, like she is so articulate" for example, which is something that I get, like a lot of people tell me that I am, and, or for example, when I'm in class and I'm engaging with my professors and answering questions and just, and all that, I feel safe talking about that because it's my special interest.

Host (17:07):

I just... I'm in my world. I love it. I love talking about autism and, neurodivergences and psychology. I just, I love it so much, but when you put me out of that, I just, I don't know what to say to people. I rely on scripting so much, so much, and I rely on my observation skills and just sensing how the person is and what they expect me to be. So I also rely a lot on mimicking. So I many times I just, I see how they're acting and I end up like blending in with their personality because yeah, I can just pick up all of those tiny things... Whoa, that was so loud. Sorry. yeah, there's a bird that is just like, hi bird" ...because social and directions are so hard for me. And I know it's, they are so hard for many of us and there's a lot of elements happening and I'll probably make an episode about this because I feel like it calls for an entire episode on its own.

Host (18:33):

But I'll say this now that sometimes is... I feel like what makes social interactions hard for me are a bunch of things. Like one of them is that is the sensory differences. So if we are in a loud environment or if the person like speaks where for me, or loud, it's really hard for me to concentrate on what

they're saying. Or then there's another thing that it's with my auditory processing. Many times just someone says like, "Oh yeah, have you seen that movie? Whatever, whatever." And I hear "blah, blah, blah, blah, blah, blah, blah, blah." And that's about it. So I'm like, "sorry, what?" "Oh yeah, the movie." And they repeat it. And you're just like, "yeah, I don't understand what you're saying. So I'm just going to nod and smile and hope it isn't a question." And it's always a question in my case, at least. It's always a question when I don't understand what someone is saying. It's always a question which makes me even like leaves me being even more awkward.

Host (19:46):

And then there's the interest part of it... I don't mean to be mean, but there are many, many, like small talk, social interactions that happen, especially in places like in, in work environments or college environments that I just don't want to have, because I genuinely don't care about them. And I say this with the nicest intention ever, because it's just, it's not that I don't care about the person. It's just that I prefer being by myself or reading a book or listening to music, or just like talking to someone that I really care about because I value my time and I value the energy that takes me to engage with people, which is one of the reasons, and this is completely unrelated, but I'll say it anyway, this is one of the reasons why it takes me so much to get back to people, whether that's on like DMs or emails, because I like sitting on my computer and just thinking what I want to say.

Host (21:09):

And I want... I like paying attention to what the person is saying. I don't like answering just for the sake of answering. I don't like talking for the sake of

talking. It's just, it makes me feel so uncomfortable and I genuinely lost lose interest and it, and I get it. I get it. It translates into like, "Oh my God, you are an awful person." And yeah, it's a matter of just, I don't feel comfortable talking about things that don't matter to me, such as when it comes to small talk, right. Because I feel like maybe that can be translated into, "Oh my God, you're an awful person. because when someone tells you something it's important to them, you don't care." No, that's not what I'm saying. I'm talking about specifically when it comes to small talk in these environments, like things that when people talk about the weather, for example, like, Oh my God, I'm not going, like, I don't want to listen to you talking about the weather, but if you like come and say like, "Hey I'm, can I talk to you about something?"

Host (22:21):

I'm having a hard time with this and this and this." And if I have enough head space to do it, I love listening to people. And I love interacting that way. The way that I link all of this that I said with changes is that when something like this change happens and we are, we have to be exposed to something that we that's unfamiliar to us, and again, it opens up a whole new array of possibilities. And now a whole lot of questions that we, that we must come up with the answers as we go, which means no preparation, no scripting, no masking, no nothing. And that's another layer of stress that we have to deal with on top of social interactions being uncomfortable for many of us, and awkward, and on top of the sensory differences. And, and on top of the work that we might have to do or paying attention in class or learning something, it's just, there's so many things happening.

Host (23:33):

And so many things to keep up with that... If you break it down into all the, all the processes that are happening without us not really like paying attention to them, it makes sense that we end up being so overwhelmed or so exhausted, or that we have a knee-jerk reaction to changes. I mean, I know that it's called cognitive inflexibility. Like we, many of us just tend to lack the ability to be flexible and adapt to changes quickly. And I get it. Yeah, I get it that... it's not fun for us. It's not fun for people around us, but it's definitely not fun for us, but it makes sense. And there's a reason, and there's a very valid reason why our reactions are to avoid change as much as possible. And while our preference for novelty or familiarity is also on a spectrum and also fluctuates so much, depending on so many things.

Host (24:48):

It's important to highlight that for many of us, it's generally like debilitating to consider change. And in for many of us, it it's, it generally, generally prevents us from doing things. Because if we think about things like in a "win or lose" ratio we end up realizing that we lose way more than we gain so we ended up not doing things and this, and when I say things, it can go from getting a job to going on a date, or just like walking your dog to the park because it means change. It means unsafety. It means "so many things can happen and that we have no control of." And we know what happens to us when things are out of our control.

Host (25:55):

So much, so much of this behavior comes from this hyper-awareness and self-knowledge of knowing what happens to us and how we react when certain

things happen in a certain way. So, for example, I'm someone that isn't comfortable walking around, like outside alone. It's just, it's something that I don't feel comfortable with. And I'm trying to work on that because I want to travel and I want to do so many things that involve being alone and navigating the world alone. And one of the things that is so scary for me is that when things get overwhelming, I need help. I need to ask someone to help me, like to remove from the situation. And if I'm alone... And many times I don't know how to communicate that. Me having to tell someone like, "Hey, I'm Autistic. I'm having a very hard time. I need you to help me." Most times. I can't even say that. But if I'm with someone that knows me, I know that I can tell them, "please get me out of here"

Host (27:17):

and they understand what I'm saying. So, for me, going outside, it's something that I'm working on and something that it's massively, massively challenging, precisely because so many things can happen. So many unfamiliar things, so many things that are out of my control. And I know what happens when these things happen. I know what happens to me when there's so much going on, that I can't control and is that I meltdown and having a meltdown alone or by myself in the middle of somewhere it's so scary. So scary... just thinking about it. It's so scary. Yeah.

Host (28:04):

I feel like a lot of people, they see these behaviors, you know, and like, "Oh my God, you're such a control freak. Oh my God. Just get over it or please be flexible and adapt. It's that easy," but it's not easy because there's so many things that could happen as a result of new things happening around us.

Host (28:32):

That it's, yeah. It's not easy. I wish I could, personally, like I struggled with it so much and I so wish I could just be like, "yeah, whatever changes are cool, because we don't know what's going to happen." I don't get it. Sorry. I don't get it. And in my case, last month, I went through some periods of intense anxiety, like paralyzing anxiety, debilitating anxiety. That just... it was such a hard time because of all these changes and... and I'm lucky enough and privileged enough to have resources, to be able to have...I have a psychiatrist. I have a psychologist. I have a lot of people that I can count on if I feel bad. I have literally someone that I can call if I feel overwhelmed that I know that's going to help me calm down, but I know that's not the case for many of us.

Host (29:40):

So to be like, "Hey, just come down, just take it easy" it's not easy. It's not easy to be able to go to that place, that fast, that without processing, without integrating what's happening without thinking about what it means this new change, what it is, what it's requiring of us, what it's being expected of us. What it's just, again, we need time to process things. Like, many of us don't know if, when something like this happens, if we are going to be able to handle it, that's the thing. And that's scary again, for the reasons that I stated, because we don't know if we'll have a meltdown or shutdown and who's going to be there. And I, again, I'm trying to be so understanding with the people around me and that are impacted with all of this inflexibility. And this reaction to say no to changes, but seriously, I'm trying to invite you to see it from this side of the road, which is that unexpected changes mean that we don't know if we'll be able to deal with it.

Host (31:07):

We don't know if we'll be able to deal with the stress of just like socializing and all that. We don't know if we'll be sensory overloaded the second we get to that place. We don't know if we have a meltdown or a shutdown and who will be there to help us out if we will lose speech, if we will struggle with, I don't know, like so many things, there are so many things that play a role in this. And that's why too many of us, too many of us, the idea of like, "Oh yeah just a heads up...this thing changed" just throws our systems into fight or flight. And it makes sense. I feel like that's what I'm trying to communicate is that, again, I'm trying so hard to be understanding because I know that it can be tough, but seriously, it makes sense because it threatens our safety or emotional safety, our "all kinds of" safety.

Host (32:21):

Just think about it. If you're non-Autistic and you're listening to this, and whether you're thinking of your Autistic partner or your Autistic kid or sibling or whatever, I'm pretty sure that you can think of many moments that you're like, "Oh my God, how can they just get over it?" Would you be able to get over it that easily? If it threatened your safety, if something would impact you in so many ways, if the tiny thing would mean so many changes for you. And so many things that impact, not just the moment that you'll be there, but probably at least the next 24 hours. Because if we go to a place that, and like unprepared something unusual change happen, and we go there unprepared, and we end up having sensory overload, we're going to need time to recover. If we end up having a meltdown, we're going to need time to recover.

Host (33:29):

So again, for many of us, you say "it's just a tiny change. Get over it." Or you say like, "come on. I know I said we were going to go to the store, but now we're not." And... For you, it's just five minutes. But for us, sometimes it ends up being 24 hours of feeling the impact, the aftermath of that tiny change in our bodies, in our brains. I've been absolutely completely paralyzed by change in a way that ends up impacting my projects, my social skills. I end up disconnecting from things because I lack resources. I start to feel tired all the time because all of my energy is being used to process all of these changes, all my energy, all my mental energy, all of my emotional energy is put there. It's like, my brain is like, "okay, we need to integrate this. We need to adapt to these things, just forget about everything else." And you're like, "Whoa, wait, I can't do that. I need to eat. And I need to shower and I need to exist. And there's people counting on me."

Host (35:01):

Again, I'm lucky. And I say lucky that I don't have kids, I don't have a husband. I don't have a partner. So, no one relies on me. So, I don't need to mask all of this discomfort because again, it's just, it's just me. So, think about it from an Autistic parent perspective or someone that has to provide for their family. Just like think about what it means for them to not be able to keep up with all the changes that are happening. And if you are able to visualize that, can you see that it's a hundred percent understandable that they ended up melting down over a change? Or they end up shutting down or that they live in perpetual autistic burnout because of that? I don't know, just putting it out there.

Host (36:07):

Because I know that I've received, and I continue to receive, so many messages of non-Autistic people saying things like that saying like, "Oh my God, my partner is autistic. And they can't handle a tiny thing. I can't even change the furniture of my house without him or her freaking out about it", "Oh my God, we can't eat a different thing for breakfast because they end up like shutting down and I'm sick of it." Like, I get it. I get that it would be very annoying for someone, but instead of thinking about it like that and how it impacts you, maybe you could start thinking about what is impacting them to act that way, to be so, yeah, to be so reluctant to change. And maybe when you think about things like that, you can ask them like, "Hey, I've been thinking about changing the furniture of our house. I don't know. I don't like it anymore, but I know that you struggle with changes. So, let's say, can we just like, try to change this table first, and this table only, and let's see how it goes?" And there's a very good chance they, maybe are like, "okay, fine", like, that's, that's what I do. And like, "okay, fine. Just that table. And we'll see how it goes." And it's easier to integrate one table moving to another place than the entire thing, does that make sense?

Host (37:54):

While many of us have the ability to compromise and many of us are so used to people-pleasing that we end up saying, "yeah, no, it's fine. You can change whatever you want," but we are genuinely, generally uncomfortable on the inside and it ends up manifesting in other ways, I feel like it's so necessary. I feel like this is something that should be completely like, figureoutable... I invented a word.

Host (38:28):

But yeah, I feel like it's talkable. You can talk about it and you can like find middle ground, I think, in those scenarios, right? That it's just, it's another way that this fear of changes can manifest. So the overall message that I wanted to give with this episode is that one, I wanted to give validation to Autistic people listening to this. Two, I wanted to provide some kind of explanation, according to my understanding of why things are so scary, change, things like unfamiliar, things are scary. And three, I wanted to give this message in particular, which is that within control, I feel like changes can be very good and I want to encourage you, the same way that I encourage myself to shake things up a bit every now and then. I'm Autistic, but I also have ADHD and that means things can't stay the same for too long because otherwise I start to get bored. And if I get bored, I get cranky. And if I get cranky, I get angry. And if I get angry, I get mean, so it's not really a good scenario. So yeah, I, I do change things up a bit. I do change my routines. I do change the things that I eat or the music that I listened to within things that I know that they are safe for me. So, sometimes I'd be like, "Hey, I'm going to eat this thing that I haven't eaten in a while," but it's not a new food per se. Like it's not a new food. It's just something that I haven't been eating in a while. Does that make sense? Like, it's, it's a new thing, but it's also a very familiar thing.

Host (40:39):

Like, that's my recipe to try new things. And shake things up a bit. So, I feel like an advice that I would like to give you is that if you feel like your rigidity and inflexibility causes you discomfort, which can definitely be the case, you can be like, "I hate this. I hate feeling unsafe with everything around me. I want to feel safe with changes because I like changes." I feel like a good way to get used to

that is just changing things, one step at a time. If you want to change your hair, for example, well, maybe, maybe change your, like, dying your hair and cutting your hair at the same time might be too much. Maybe you just want to dye it first and then cut it or whatever. I hope that makes sense. The same goes with things, with other things that are within your control.

Host (41:49):

Like I don't know, food, music, hobbies, special interests, people. I feel like when we are able to control the things that we can control is that when we start to feel safe with ourselves and we start to feel more confident with ourselves and how we navigate the world. And I think that's so important for us, especially because many of us don't have many autonomy or is constantly, constantly judged or doubt or so many things that that's another topic for another episode, I think.

Host (42:33):

So yeah, I think I'm done. I don't know. This is a weird episode. I think, I, I don't think it has much structure and it was mainly just me rambling. But yeah, I, I was feeling kind of stuck with my podcast precisely because of all the changes and all of that. And yeah, I feel comfortable. I hope I am able to record episode five soon and it doesn't happen in a month.

Host (43:09):

So yeah. Thank you so much for listening and thank you so much to Tiimo for sponsoring this podcast. And if you are interested in more of my work, you can find me on Instagram as @theautisticlife. You can find this podcast's Instagram @theautisticlifepodcast. You can also find me on Patreon and I also have a

store with a bunch of eBooks and another resources that are on Autism and neurodivergences, and it's full of things autistically done by an Autistic person. Which is me. I'm the Autistic person. Okay. now I'm rambling. Again, thank you so much for listening and until we meet again, please stay safe!