

## Autism with Maddie White

### Speaker Key:

**VO** Voiceover

**CB** Chantal Boyle

**MW** Maddie White

00:00:00

**VO** Welcome to The Sunflower Conversations, where we explore the Hidden Disabilities Sunflower and its role in supporting people with hidden disabilities.

**CB**

So, hi. Let's see who we've got joining. I'm Chantal, and we are having our first Instagram Live with Maddie White, and very excited. So, this is part of the Instagram Live, but it's part of our Sunflower Conversations podcast. We've got a podcast available for everyone to sign into, to listen to when you're having a walk or you're cleaning or driving or commuting. That's when I like to listen to my podcasts.

So it's really lovely to see how many of you are joining. We're just going to wait for Maddie. Our first Live is with Maddie White, and it's titled Autism with Maddie.

This is very exciting, first Live. Here we go. And here's Maddie. I was just about to clap then. How are you doing?

**MW**

I'm good, thank you. How are you?

**CB**

Yes, I'm good. I'm really excited, a bit overexcited actually. I was just explaining to everybody how this is our first Live. It's part of The Sunflower Conversations podcast. I'm one of the hosts, Chantal, on that, but you will hear other hosts on it. And it's our opportunity to talk to sunflower wearers about their own lived experience.

Maddie has very kindly offered to share her experience with us and with all of you. Maddie is 21, recently graduated from university with a bachelor of arts, a BA in theatre and performance. So, congratulations, Maddie, because that doesn't sound like an easy achievement.

And so, whilst Maddie was at university, she discovered or received a diagnosis

that she has in fact got autism. She's got ASD. But in the runup to that, there were other misdiagnoses and we thought that it would be really helpful for Maddie to share her experiences of what they were and how she was impacted by that.

00:03:07

So, Maddie, can we start off with you telling us, prior to getting your ASD diagnosis, what was life like for you before?

**MW**

So, I kind of had always had really just quite significant anxiety. This had always been a thing since I was little. I'd always just suffered from anxiety in school, had some difficulty with making friends just because I found it difficult to fit in with people. So it had been something that had progressed.

It started in primary school, progressed more into secondary school, which is where I was dealing with a lot more what at the time were described as anxiety attacks and panic attacks. So I dealt with that a lot throughout, especially throughout exams, and then it worsened a lot more in Sixth Form.

So it was in my Year 12 of Sixth Form when I was 16, in January of 2019 I was diagnosed with mixed anxiety, depression and panic disorder.

**CB**

I was saying that's a lot. For a young person, that's a lot.

**MW**

Yes. So that was kind of all bundled into one sort of neat package with one doctor's appointment pretty much, just explaining everything that was going on.

And then, as a result of that, because of how bad the anxiety and everything was, I was then signed off of school for a month to try and manage the impact of what was going on and work out how and what was the best way to approach dealing with these situations and creating an intervention plan to get me back into school, because I think that was one of the main things, was getting me back into school, getting me reintegrated.

00:05:13

**CB**

[Unclear] how to do that? So, what were the things, what were you experiencing that made your doctors come up with all these diagnoses, with panic disorder, mixed anxiety? What were you displaying and how were you feeling?

**MW**

I think in displaying terms, it was just increased anxiety, which in my sense presented in not being able to function well in lessons. In general, I loved school. I loved the learning part of school, but I didn't thrive in the environment of school. I always found it very overwhelming and stressful. So, a lot of the time I would be in the lesson to do the learning and then as soon as it got the bit, right, we're going to sit down and do our work, I'd move into the learning support centre at my school and do all of my written work there.

So, that was one of the procedures that was put into place to try and manage it. But in terms of it presenting, it was just a lot of generally feeling overwhelmed, which when that comes to me, that comes with a lot of tears. And even [unclear] not necessarily that I'm feeling upset or anything like that. It is purely just my instinctual reaction. I won't even necessarily realise it. Sometimes I will just start crying, and I don't know that it's happening. But that's just the instinctual reaction.

So, that was one thing that was presenting, which obviously crying sort of comes hand in hand with sadness. So I think it was inferred, because I found it difficult to explain what it was that was causing these feelings and these emotions, because I didn't really understand it, from people putting those two and two together, I think it presented itself as, oh, she's upset, she's feeling sad all the time, she must feel low, so therefore she needs to be diagnosed with depression, for example.

00:07:15

**CB**

Yes. So you were 16, weren't you, when you received those diagnoses?

**MW**

Yes.

**CB**

But even in spite of everything, you were still managing to do your schoolwork, but it was under a lot of stress and obviously emotional turmoil for you. So, when you received the diagnosis, what happened then? How did they support you? Antidepressants?

**MW**

So, yes, I was given antidepressants and referred to go to counselling, which was a decision made between me and my parents that I wouldn't pursue it through CAMHS, that we would pursue it through a local private practitioner because it was closer to my house. And if I'd had to go to CAMHS, I think it was a half an hour to 40-minute journey every [unclear] to go.

So for me, who was already dealing with that stress, then having to think, oh, I've

got to travel on my own to go somewhere, that part of additional stress... Yes. So I was put on antidepressants. I think I got put on them pretty much from that initial, here are your diagnoses, this is what we're going to do to help.

So initially I think I was put on sertraline, if I remember rightly.

**CB** I've heard of sertraline. It's quite strong, isn't it?

00:08:54

**MW**

Yes, and I think before I was put... Because I think of how, or at least the way it was presenting, how bad my mental state and everything was, I was put on the maximum dose for my age group, which I think was 150 milligrams. So I'd gone from nothing to all of a sudden, 150 milligrams is something that I've never taken, and I'm only 16, with not knowing what's going on.

**CB**

That's a heavy-duty drug, isn't it? And your body must have felt like it was being assaulted, your body and your mind.

**MW**

Yes. I think for the first two weeks, because of how intense an effect it had on me, I don't reckon I probably left my room or [unclear] for the first two weeks.

Because of how badly it was affecting me, I was on anti-sickness tablets to try and manage to get me to be able to eat properly, enough to take to the pills correctly. And it was just managing all of these little things that came with it that I wasn't necessarily I suppose expecting to happen or to have.

**CB**

I would imagine, after receiving such a strong diagnosis like that of, like I said, mixed anxiety, panic disorder and depression, you would hope that whatever treatment you got was going to make you feel great.

**MW**

Yes.

**CB**

Not worse.

00:10:35

**MW**

Yes. I feel like it's one of general bad things is like, oh, you probably won't feel better until three months' time, and then sometimes it'll go to six months' time because there's... I remember, because of how not negatively I reacted to sertraline but how I wasn't dealing with it well, it was talked about pretty much straightaway with my parents and the doctors to have me swap to a different one because the child that we have is not the child that we know right now.

Especially in terms of me and my emotions, I feel like my emotions are very much like zero to 100. I'm either not bothered by something or the emotion that I feel was the most intense every single time I feel it, if that makes sense. So, if I'm happy, I'm crazy happy, completely overjoyed. If I'm sad, it feels like I'm never going to be... Like this is the saddest I'm ever going to be, and so on and so forth.

So, kind of going from having these intensely felt emotions to all of a sudden just not feeling really anything, for me it was almost like this internal switch had been shut off, and in myself I felt like I was presenting a different self to who I actually because of how it was reacting, obviously, with my brain chemistry and my body and everything like that.

**CB**

So, that's you at 16. You were having quite a torrid time. And now you're 21. You've graduated with this BA from university for the theatre and performance. You've got a job, and you've received an autism diagnosis. So, what took you from there to where we are now, and how did that occur?

00:12:43

**MW**

So, when I first went off to uni, I went to uni in September 2020, so it was just after we'd come out of that long period of March [unclear] lockdown when they started saying that you can transition back into education.

So I think I was a little bit worried about it but I was like, okay, I'm just going to go and I'll just see how it is. So I went off to uni in the September of 2020. I was trying to sort out my disability allowance, my disabled student allowance, but because of lockdown and COVID and everything being so up in the air, the information around it and people being able to actually help you, I didn't have the right information.

You had to fill out a specific GB form that I didn't have because I didn't know you had to do it, but I didn't find that out until six months into my first year. So I think I started to receive my first support that I should have been getting from my original diagnosis of mixed anxiety... I started my mentoring support. It's called mentoring, but it is pretty much like counselling.

It can vary from person to person, who you have, but predominantly, the lady that I had, we focused a lot on talking about my feelings and emotions, which I think is always something that I have always really struggled with. So, she was

trying to help me to start talking about that and we were talking about, in general, my anxiety and how my anxiety a lot of the time is linked to what's going to happen in the future, what am I going to do next, what if this happens, what if that happens.

It's not anxiety like... I'm trying to think of an example. But I have a job interview tomorrow, so [unclear], not that kind of anxiety.

00:15:06

**CB**

It's needing to know what's coming next. You need to know what the plans are so that there's no surprises. It's like, I'm going from A to D, but I'm going to go via BCD to get there.

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**MW**

Yes. So, I was talking her through all of these things, and she specialised in anxiety and then also she specialised in ASD and ADHD. So, while she was speaking to me, she was like, look... I worked with her for around four months, five months maybe, and it was coming to the conclusion of our sessions, because you have a practitioner for the duration of the university year, so July to the following June/July, September to the following June.

And then you either can choose to have that person in the next year or you can move on to someone else. So it was coming to the last few appointments that I had with her, and she said to me that she thinks that a lot of the ways that I present and also the way that I speak and that I articulate things and everything, she was like, I don't think that these panic attacks that you have are panic attacks.

I think that they're something more like sensory overload, because the things that you're getting triggered by aren't things that would be inducing a panic attack. They would be inducing some sort of sensory response.

00:16:41

So we talked over a lot of the things and everything and that kind of thing of why she thought that, and then she just said, look, speak to your GP and see what they say. So, from then I spoke to my parents. My parents help me a lot with everything and sorting everything out because I don't...

**CB**

It's what they are there for.

**MW**

So I spoke to my parents and they were like, okay, well, we'll speak to the GP and we'll get a referral letter. So I think my initial appointment with the GP was in, I want to say September of 2021, and that was the initial asking for a referral, seeing what the next steps were.

So, on the NHS at that point I think it was a three and a half to four-year waiting list for...

**CB**

A long time, if you think about how significantly it's impacting your life.

**MW**

So I was really lucky in that my parents were able to do it privately. So we went down the private route, which is a massive privilege. I know a lot of people don't have that, so I feel very lucky that I had that experience anyway.

So we booked the referral, and then I think I had my initial... I'm trying to think of the exact time. I don't know, at some point...

**CB**

Don't worry about the exact time.

**MW**

I had my initial appointment. So the way that the assessments work, which I didn't know when I went for my assessment, is you have a pre-assessment, which is a 45-minute to an hour appointment where you do a rundown of pretty much you and your life from your point of view, is probably the best way to describe it. So you talk them through your experience at school, your experience with friends, friendships, relationships, just the essential sorts of things about you.

00:18:53

And then you move. So, after that you then fill out a... I can't remember the extra name if it, but it's a 50-question questionnaire, so it's like a multiple-choice question. So it's like how strongly you agree to the statement. So you circle how strongly you agree, send that off.

So that was the pre-assessment. And then from that I then, after collecting the data [?] and everything from that, they were like, yes, go ahead, we're going to go for the full assessment. So I had my pre-assessment in June and then I had my actual assessment in December of 2022, last year.

So, this time last year I would have had my pre-assessment done and I'd been waiting for my actual assessment to come around. So, in my actual assessment,

that is a two and a half to three-hour conversation.

**CB**

Let's hear about that. So, what happens? You go into a room, or did you do it online?

**MW**

I did mine online. So it was just me and Mum, so my mum did it with me because they recommend that you have a parent or a [unclear] that has known you since you were little that who can comment on how you were really little, when you don't necessarily remember it.

00:20:29

So, I had it online, so it was over soon, with my mum. So, yes, we did it in a hotel room because Mum had to come up to see me at uni to do it, because my university wi-fi wasn't very good, so we did it in a hotel room, just sat together doing it.

And, honestly, I've been through my degree and everything now, and I can still say that I think that doing that assessment will be the most difficult thing I ever do because... It's difficult to explain how hard it was, but some of the questions, you almost had to think about me, as in myself, but then also Maddie, what does Maddie look like and how does she present herself to other people.

So I was having to think about from my own understanding of myself, but then also how that translates into what other people understand. So it was questions...

**CB**

That's very complex, isn't it?

**MW**

Yes. And I knew it was going to be difficult, but I was sat there, and I'd been in uni all day, like, this is all a bit much.

**CB**

I guess you're worrying, aren't you? Can I ask, at this stage, do you have a hopeful outcome to be diagnosed with ASD, or did you not want to be diagnosed, or did you just really not know what you wanted?

**MW**

I think I didn't necessarily know what I wanted, but if I had to pick the outcome, it would have been to get a diagnosis, purely because the understanding that I got and the validation that I got that I [unclear] stuff about my brain and that I'm not just not feeling the correct way or not dealing with things in... I say the correct



way in inverted commas.

00:22:40

I don't mean the correct way, but the way that society creates that you should be doing something. I was never able to do that, so getting the diagnosis for me was just that validation almost that I understood that I was right, in a sense. It's difficult to explain, but it gave me the understanding that, no, you actually do understand your brain. And now that we've told you...

**CB**

I'm not anything wrong. It's just you're trying to navigate in this world and scenario that hasn't been set up for your brain. However, there are ways in which you can share, like we're doing now, you sharing your experience to help other people either understand what it feels like to be autistic and trying to navigate this world, or a young person who is thinking, I don't understand why I'm feeling like this, and actually to look for some answers.

So, what would you say has been the difference now to some of those scenarios that you found really overwhelming and overstimulating in the past before you realised that you are autistic? What has changed now?

**MW**

I think one of the main things that I think has changed, which isn't necessarily a change in terms of how I approach the situations or deal with the situations, is more just the understanding now that I shouldn't almost beat myself up about all of the things that I used to.

00:24:34

And especially at school when I couldn't function in lessons and I'd get annoyed that people were talking, and I'm like, well, other people are having conversations, why can't you just have a conversation? What is it that is bothering you? Why is it such a problem?

Now I look back on it and I think, well, it wasn't made for me to be in that situation, and now that's fine. So I think especially now I just give myself a lot more time, and I'm still trying to get better at it because there are times where I do not give myself the amount of time that I should, but especially now, I'm definitely trying a lot more to give myself the time.

So, this work isn't happening right now because you're overworked. That's okay. Have a 20-minute sensory break and then come back to it, rather than constantly before I'd be like, no, I need to do it, I need to do it, I need to do it. And it just wouldn't happen.

It's a more caring approach to me, rather than a caring approach to what other people want and what I think neurotypical society and everything wants, if that

makes sense.

**CB**

It does make sense, yes. And do you feel that if you had known this, secondary school is when it started to accelerate, these feelings and emotions, wasn't it, do you think you would have had a different experience?

**MW**

I was really lucky because of the size of my school, that they were happy to make the amount of accommodations that they did for me without me having any diagnosis at all.

00:26:24

I had that pastoral support within my school from age 11 to 18 when I left. I had that constant engagement from the school at all times.

So I think that was really good, but a lot of the challenges that I face, as much as I face some challenges outside, a lot of the challenges that I face are contained within myself and my own head because I put pressure on myself to be and act a certain way because I think that that's what's appropriate. But then, because of that, I'm then not acting or being like me or doing what I do.

So I think a lot of is, as much as there are a lot of external pressures that I still feel, for me, a lot of it I think is overcoming the mental battle within my head of what's been ingrained into me the whole time.

**CB**

That's it. You're 21 now, so you've got a lot of unlearning to do and redirect your neural pathways in a sense, haven't you?

**MW**

Yes, because as much as I'm trying my hardest to unwrite those brain patterns and everything, still, because it's been ingrained in me since, what, four years old, because this is the first year that I haven't been in education since I was four. So I haven't not known the you sit in your chair and you do your work and you get on with this in a certain way, then you go to break, then you [unclear]. So I've not known that.

00:28:24

So, now I've worked through that as a neurotypical presenting person, but then in turn, well, externally neurotypical presenting person. Internally, definitely not. And in turn now I'm having to kind of work out where to go because it's this almost internal fight of this because I know I've learnt it my whole life. I want to break that down because I don't want to live like that anymore.

**CB**

The other thing is, Maddie, you've just really encapsulated that really well because, as you said, earlier on you said that you need to know what's coming next and how you're going to navigate to the end result. And now you're not in education at all.

So now you've got your diagnosis. You understand that you're neurodivergent. But also, you're not in this education environment anymore. So, has that been a bit mind-blowing, getting a job and not having the set rules?

**MW**

It's been so scary because it's been [unclear] change I've ever had. I still don't think I've fully transitioned into it. I'm hoping that I'll get to Christmastime, and I'll feel like I sort of get it, because right now I still don't think I am fully used to it yet. But my mum and dad will probably tell you a million times that all I ever go on about all day, every single day, is, oh, what am I going to do next? I need to do this next. Oh, I need to start this. This is what I'm going to do.

And all I am worried about is what's coming next. I find it difficult to live just within that moment. Yes.

00:30:32

**CB**

I think in time that will come, because another thing is, yes, you've had a seismic shift in actually your whole identity, who am I, and the way you approach everything.

But the other thing to say is that with every decade of our life, we kind of shake something off. It's a little bit like a butterfly really slowly emerging. So, with every year that passes by, every birthday, you become more you and sort of own yourself.

So it will happen. Maybe Christmas is a bit soon, this pressure that you're putting yourself under.

**MW**

By Christmas, I more mean that I'm used to getting up and going to work every single day. This is my first real world job, which isn't a part-time job, which is kind of scary. But I feel like I'm managing with it quite well.

**CB**

Well, you've got a good job, haven't you?

**MW**

Yes.

CB

What's your job title?

MW

So, I'm a learning support assistant in a specialist education school. So I work with children and young adults with learning disabilities or epilepsy [?] or complex additional needs. So, I've been doing it for six weeks, so I'm very new to it. But I'm really enjoying doing it.

00:32:11

CB

Good. I bet you're brilliant at it. So, listen, I am conscious of time. We've been chatting for half an hour. But have you got any advice for any other young people that have had a similar journey but haven't either got their diagnosis yet and they're just really having difficulties coping with life and the challenges that are out there?

MW

I think just having the confidence that you know your own brain and that you know your own self. So, even if it takes 100 times to explain it to one person, that this is how I feel, this is what I think is going on, eventually you will meet the right person who will listen and will understand, and then will be able to then take that forward.

And it might be my case that it's when you're 18 and you go on to do it yourself. Also, I needed a lot of support to sort it out, but I've got to a point now where I feel like I am starting to understand. I don't understand yet, but the steps are going. So I think just having the confidence that you are you and you understand yourself more than anybody else is going to understand you, and that you just go forward and explain it to people and eventually people will understand and they will help you.

And also, give yourself a break and don't beat yourself up about things that a lot of the time aren't actually in your control.

CB

That's great advice. That's sound advice. And of course, we would say wear the Sunflower in situations where you feel it's going to benefit you most as well. But that advice, Maddie, is excellent advice to end on.

00:34:17

So, I just want to thank you for being my first guest on Instagram Live, and thank you to anybody who joined, and we will post this on our grid so that people who didn't have the opportunity to join can watch it back.

**CB**

If you are interested in any of the advice in this podcast, please follow up with your GP or healthcare practitioner.

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**VO**

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Making the invisible visible with the hidden disability sunflower.

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