

Autism and ADHD with Jen Hankin

Speaker 1:

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

Chantal Boyle:

Welcome to The Sunflower Conversations with me, Chantal, and my colleague, Sandee, who is in Australia.

How are you doing Sandee?

Sandee Facy:

Really well. Thanks, Chantal.

Chantal Boyle:

Sandee and I have the pleasure of speaking to Jen Hankin today. Jen is a musician who composes, teaches and performs. Her creative skills extend to fine arts, photography, videography, fashion design and writing. Jen is also autistic.

Jen, welcome to the podcast.

Jen Hankin:

Thanks so much for having me today. Yeah, so I have a long and winding history with diagnoses, particularly missed opportunities for professionals to pick things up. I started seeing a psychologist when I was seven, and I was diagnosed with the very scientific condition of a very active imagination. Had that professional looked a little bit deeper, I might have got some earlier help. From that point on, I was in and out of school counsellors offices up until I was at uni, and I thought, "Cool." My mental health is getting worse and I need to get somebody to do something more than just talk to me about this, so I started seeing the university psychologist. They said that I was just depressed, and I thought, "All right. I'll go with that." That didn't really help. I tried some medication, and it ended very poorly. I tried another medication, and it ended very poorly.

I cycled through a few psychologists doing the medication thing, and then I found somebody who was actually willing to listen to me. This was in 2017. I went to her and I said, "Hey, I think I might be autistic. Here is a big list of reasons why," and she said, "Oh, I mean, you don't really present autistic, but you should be getting better, so we'll give the test a go. Why not?" and then, at the end of it, she was like, "Oh, yeah. Oh, yeah. No. No. You're very autistic." Even then, it didn't fit everything.

When my previous psychologist retired, I saw a new psychologist, and she was like, "Autistic, but also have you considered a ADHD?" Up until that point, my understanding of ADHD was like 10-year-old boys who couldn't sit still in class and just ran around at hyper speeds until they crashed. I'm not a 10-year-old boy who does that, but we did a screener, and it very clearly came back that, oh, yeah, I need to go see a psychiatrist for this. From there, it's taken me almost two years. Two years? Yeah, almost two years to finally get somebody to consider medication for that and not just give me depression meds.

Chantal Boyle:

May I ask what are some of the traits that you had when you went with your big, long list to the specialist, and then again with the ADHD? What are you hoping that the medication will do to you? What difference will you hope it makes?

Jen Hankin:

Yeah, so I'll start with the big list of long traits. It's been a while since that meeting, and I've mellowed out a bit from analysing my behaviours, but the two big ones were, in a group of people, I would always stand on the edge until I'd observed the room and everybody in it, see how they're interacting, then take on those behaviours so that then I could fit into the group. I often did that very unsuccessfully, but I thought that's how everybody did it. It turns out it's not. Then the other big one was, for the first 12 years of my life, I had to have my socks inside out because the seams were like little razor blades against my toes.

Chantal Boyle:

Yeah, so sensory.

Jen Hankin:

Yeah. I figured out how to wear socks without them upsetting me, but they still upset me quite a lot. With ADHD, I suppose the big thing that I struggle with at the moment is brain fog. I have a very busy brain at any given time. It's got 60,000 thoughts all kind of rushing through it and, as I've aged, it means that I can't hold onto those thoughts like I used to be able to. I can't remember anything. My concept of time has flown out the window. I patchwork my life together with a very complicated system of paper calendars, digital calendars, alarms and just an underlying undercurrent of anxiety trying to remember that I have things to do.

Chantal Boyle:

Because I think there's several different types of medication for ADHD, isn't there, for somebody who chooses to go down that path. Would you say that those experiences and feelings, the brain fog, that's accelerated as you've got older then?

Jen Hankin:

Yeah. Definitely. Definitely. I'm really hoping that medication helps to ease some of that. I'm not expecting a magic pill. I would just like to feel even 1% better would be a huge improvement, but I don't know if it does that yet because I have only just started that process. I'm on my third psychiatrist. The other two gave me depression meds and said that I wasn't allowed to have a ADHD medication because it's a restricted substance. I think the implication was that I was drug-seeking, and I don't even take Panadol.

Chantal Boyle:

Yeah. That's not going to help you at all, is it? Speaking to people like that who imply that you're drug-seeking when you're not is outrageous really.

Jen Hankin:

Yeah.

Sandee Facy:

Give us a snapshot of your education around music and where you've gravitated to, I guess.

Jen Hankin:

I was classically trained as a flutist. I wouldn't describe myself as a classical musician anymore though. I went through a system called the AMEB, which is the Australian Music examinations Board. I have mixed feelings about my education through that system. It did a lot of harm which I'll probably talk about later, but it also gave me the confidence to pursue a career in classical music. Once I finished my AMEB exams, I went right through the AMOS. I did a diploma of music performance, and I did that during my HSC, which is year 12, last year of high school. Then I went on to do a bachelor of music with honours.

As Chantal mentioned, I am very into fashion. The Emerald Ruby originally started as a fashion blog that slowly morphed into me taking photography seriously and starting to work in the field professionally. My writing also grew along that. As my photography got better, my writing also improved. My current tagline is, "Folk, flute, fashion, and feelings."

Sandee Facy:

I love it.

Chantal Boyle:

It's a lovely name, Emerald Ruby, isn't it? It just feels so rich and smiley.

Sandee Facy:

It does.

Jen Hankin:

It comes from the colours that I was wearing a lot at uni. I was wearing a lot of emerald green and a lot of red.

Sandee Facy:

... and a ruby red.

Chantal Boyle:

Christmas tree.

Sandee Facy:

Yeah. Fantastic.

Chantal Boyle:

Clearly, you're very musical. How has music helped you? Or does it help you? I mean, it's obviously something. It's your natural talent.

Jen Hankin:

That's a really difficult question for me because I think help implies that there was something, that there was a life and a feeling and stuff before music when music was always the focus. Probably, the way I would phrase the question is what would my life be without music, and the answer is very difficult. To me, music is like breathing, and the only places I feel truly comfortable are either on stage or in the practice room.

Chantal Boyle:

It's really interesting because I have heard a lot with neurodiversity that sensory overload is a real challenge and can be an issue and something that can create sensory overload is sound so presumably it's because you are making beautiful music it takes you to a really happy place instead of sound just reverberating your ears.

Jen Hankin

Yeah, I definitely have to be careful when go out because a lot of sounds all at the same time do become quite overwhelming. It's less so music for me though, it's conversations on top of conversations on top of conversations when it gets difficult.

Chantal Boyle:

Yeah. Do you just naturally hear music wherever you are? Do you hear the tones of things that I wouldn't necessarily pick up on, do you think?

Jen Hankin:

Yeah. Yeah, I think so. I'm always thinking about music.

Chantal Boyle:

You are listening to The Sunflower Conversations with Chantal. To share your story and find out more information, the details are in the show notes.

We were wondering has neurodiversity helped with your song writing and composing, teaching, performing, or has it presented challenges?

Jen Hankin:

I think it's been more of a hindrance than a superpower. I mentioned the AMEB before and my classical music education. The AMEB system is not equipped to handle students who don't think like the hundreds of years of students who came before. I, unfortunately, do not have the brain that fits in with that method of learning, so I had a lot of teachers be really confused about why I was so competent, but then also was struggling with the basics. I couldn't read music fluently. I would have to sit there and analyse my way out of the musical problems, and it was for really simple stuff, like, just one beat notes, I would have to sit there and really look at it. According to my teachers, I shouldn't have had to do that.

I also got left behind in music theory. There were some things, some terms that were said that most students just heard it and got it, and then I needed somebody to define it for me. They couldn't because they'd never had to do that for a student before. I was just seen as kind of broken and terrible. Then this continued all through my education. I have a vivid memory of sitting in my honours class at university, and I was trying to get my lecturer to define what a thesis was and what steps I had to take to write a good one because I'd never written a thesis before. I don't know what this is. We didn't do any academic writing, compulsory academic writing in my career, oh!, we didn't do any compulsory academic writing in my degree. Whenever I Googled it, it came back with like, "Here's how you write a history thesis. Here's how you write a science thesis."

Chantal Boyle:

I didn't go to university. I have no idea what thesis is.

Jen Hankin:

I mean, I wrote one, and I still have very little idea because I kind of just panicked my way to 10,000 words and presented something and got a mark that was good enough to get a piece of paper.

Chantal Boyle:

So now, you teach music. Who do you teach music to? Have you incorporated any of the things that you've learned from your own experience of learning?

Jen Hankin:

I teach. I teach students between the age of eight and late high school. Because I am very aware that one music teacher getting grumpy with a student and annoyed with a student, one time can ruin music forever, and I am absolutely terrified of being that. I have figured out a method of teaching that allows learners of all types to succeed under my tutelage.

The short story is I assume that my students are neurodivergent and have a different way of learning until they prove otherwise. What that means is that the students who have the brains that can learn in the typical classical method, they end up saying after a couple of weeks, "Hey, can we do more or can we try some harder stuff?" I'm equipped to take them there. It also means that the students who might be lacking some of the fundamental concepts don't fall behind or feel embarrassed or feel as though I just think they're broken and a bit bad. I'm always willing to meet them where they're at, and they are all very aware of that.

Chantal Boyle:

Yeah, so you really are catering for everybody, and both approaches work and, as you say, you move with the rhythm of each individual student and can then change it, mix it up, adapt it to suit their individual needs.

Jen Hankin:

Yeah. I'm trying to be the educator that I needed at their age and-

Sandee Facy:

Yeah, and that you didn't have.

Jen Hankin:

Yeah, and that I didn't have. It's really hard to not feel angry for the actions that the adults took in the past. They didn't know that I was autistic because I didn't know, and they didn't know I was ADHD because I didn't know, but it is very possible to teach in a way that caters to these neuro types without anybody having to disclose anything. When adults are in a position of power, because being a teacher is a position of power, it's... I wish teachers had more appreciation for just how their influence can affect people throughout the rest of their lives.

Chantal Boyle:

Yeah. I mean, it's make or break sometimes, the school experience, isn't it? That's sort of the beginning of your life.

Sandee Facy:

Teaching is a privilege. Well, it's wonderful that you embraced those learnings and chose to move forward and help others. I think that's very commendable.

Chantal Boyle:

I think you have a couple of pieces which are related to neurodiversity or disability. Would you mind explaining what you've done and why you've done it?

Jen Hankin:

Yeah. My most recent release is called The End of Torpor for Flute and Cello. I released it as a book of sheet music, a music video and a recording. That piece, The End of Torpor, it's about coming out of a period of burnout. Torpor is a state that animals enter just before they enter hibernation. It helps their body calm down and then they hibernate. For me, coming out of that burnout, that allowed me to write the piece. It very much felt like I was exiting a period of hibernation I thought for the last time, but I was wrong.

It's been the most ambitious project I've worked on to date. I'm a fully independent musician. I don't come from a rich family, and I have been funding my own music for the last 10 years out of the poorly-paid gigs that I'm playing and also whatever spare cash I have from teaching flute. I ran a crowdfunding campaign to get a significant portion of the money, and a lot of people contributed to it, which allowed me to make a really polished production, which was nice.

Sandee Facy:

That's great.

Chantal Boyle:

We'll then share a link to it in the show notes so that other people can listen and then, well, speak and enjoy.

Sandee Facy:

I was very, very interested in hearing your song that you play on the ukulele, the one that we talked about. If you wouldn't mind sharing that with us, maybe telling us a little bit about it?

Jen Hankin:

I've got my baritone ukulele here or, as some people call it, the cheat guitar. I love this little instrument. It really did open a lot of things musically for me. It's such a joy to play. I'm going to play a song that I wrote called An Empty Drawer. It's about the disabled experience and not knowing how you're supposed to live when you lack energy and society takes for granted that people just kind of have energy. (singing)

"I am so tired

Tired and sad

These two emotions
Are all my brain can have
Where did all my spoons to
I thought i left them here
My drawer is empty
The price of spoons to dear ”

Chantal Boyle:

Wow. I love that.

Sandee Facy:

That's fantastic.

Chantal Boyle:

What a beautiful voice.

Sandee Facy:

Yeah, it's a voice of an angel.

Chantal Boyle:

It is.

Sandee Facy:

Lovely to listen to. Yeah.

Chantal Boyle:

Sandee and I interviewed somebody previously who is autistic, and she was explaining the concept of spoons to us. Jen, I don't know whether you would like to explain the concept of spoons to our audience.

Jen Hankin:

Yeah, so the general idea is that everybody wakes up in the morning, and their kitchen drawer is full of a certain amount of spoons. To do things throughout the day, you go around spending your spoons on stuff, so having a shower might be one spoon and cooking breakfast might be another spoon. Disabled people often have access to less spoons than typically functioning people. A typically functioning person might get 50 spoons and they

can just throw their spoons around all day, but a disabled person might wake up with five or six, and then you have to make really tough choices about what you're going to spend your spoons on because, in our society, there are so many things that you are expected to do. There are so many things that you are just expected to do. And for some people, and I am included in this, I cannot do everything. It just ends in me in a very sad state not being able to function for an extended period of time.

Chantal Boyle:

You have no spoons left.

Jen Hankin:

No. I have spoons today though, which is nice.

Chantal Boyle:

I can tell.

Sandee Facy:

I'd like to ask you, as a musician who's neurodiverse, how can you be supported within your career around, say, for instance, you were just speaking about your spoons, et cetera, at shows you have, gigs, et cetera? What are some things that you'd like to tell our audience that might be a little bit different than, say, anyone else or whatever, your uniqueness?

Jen Hankin:

There are two things that I would like to see change in the industry. One is very tricky and depends a lot on more funding for the arts, and one would be fairly easy, but I doubt it will happen anytime soon. The big one is I need venues to meet me halfway. I spend an enormous amount of energy contacting venues to put on shows. If venues could do that, I would have so much more time not just to practice my craft, but also sleep. Sometimes, trying to get in contact with venues keeps me up at night. It would allow me to clean the house better, because sometimes when my brain is so busy trying to get anybody to answer me for this tour I can't clean. Which is a little deal after one day, but you leave it a week, and suddenly it's a very big deal. That's the big one.

The other thing I would like to see normalized is for venues not to play background music before, after and between musicians. I had the privilege a few weeks ago of running a show and I was given the power as to whether to put the house music on. I didn't, and people were a lot more willing to listen to the acts, and they could also talk because they could hear themselves over the silence as opposed to whatever top 40 Spotify playlist a lot of venues often put on. That was really, really nice.

Chantal Boyle:

That's just a simple change, isn't it?

Jen Hankin:

Yeah. It's a simple change. I don't know. I don't know what it is because, I mean, I really like it. There seems to be this attitude that, if the music stops, people will leave. People won't leave. They just want to hang out.

Chantal Boyle:

Is it because we've become some sort of... We've got televisions. We've got radios. We've got all form of audio and visual. Do you think organisers worry that if there's silence, like you said, people will leave? How do we cope in a silent atmosphere? Well, by talking to one another.

Jen Hankin:

I definitely think that's part of it. I think, as well, people have just got so used to there being background noise and background music that they don't even question when it's there. I don't have the luxury of not being able to question if it's there. I am so aware of all the background noise and the background music. Yeah. Having a night without it has definitely changed my perception. I was like, "Oh, yeah. Cool." I was right about this. I would like to see more venues do the same.

Sandee Facy:

I'd actually like to interject one. If you're going to make a list, please add this to the list. I think it would be really helpful if venues had some sort of schematic or map that actually showed the musician where they were going to be performing in the venue.

Jen Hankin:

Ah, yes!

Sandee Facy:

If you didn't get a chance to race over there because it's 10 Ks up the road or perhaps it's in the next town, wouldn't it be great to be able to see, "Hey, you know what, here's where we load in, the parking you have to load in, and you've only got 10 minutes," so you better be able to unload in a timely fashion." I really think that it's helpful to become more spatially aware as well, and then the anxiety of the actual show decreases somewhat. You still got a lot going on, but to be able to actually visualize, if you can't physically be there, to visualize what your potential challenges or obstacles could be. Maybe put that on your list.

Jen Hankin:

Yeah. No. That'd be great. I think it's so easy to forget that disabled people go out to spaces. I have a few friends who have mobility differences, and they are always thinking about like, "Oh, can I get in this place? Are the steps going to be too much?" That's one way in which disabled people are physically excluded from places, but then there's also the kind of autistic experience, and I can't speak for everybody because I just know my autistic

experience, but it's not often that you see somebody who is very visibly autistic in a concert venue. Probably the assumption I'm going to make is probably because that person knows that it's too loud and it's going to overwhelm them.

The other end of the spectrum is, if there is an autistic person in the venue, they're probably masking as much as they can to keep it together so that they're not loud or an inconvenience or spoil the night for their family and friends and they're not causing the drama or whatever. There are so many ways and attitudes that are perpetuated around society and societal norms that keep disabled people invisible. I mean, theoretically, if disabled people were more visible, then perhaps we would actually start to see some change.

I know that some of the rights and privileges I have as a person with a disability have been hard won by activists who have come before me. I'm on the NDIS, which is the National Disability Insurance Scheme. That's basically the government saying, "Okay. You need access to resources to be able to function and prosper. We're going to give you those resources." It's by no means perfect, but since getting on that program and having access to the tools and the funding to have different therapies and to have a support worker come in once a week to help me with the housework and also errands and stuff, this is the first winter I haven't had a massive burnout and I am the most functional I have ever been.

Chantal Boyle:

Because you've got all those tools in place. Another tool is the Sunflower. How do you feel about the Sunflower as a communication tool for people with non-visible health conditions?

Jen Hankin:

I really like it. I think it's great. I think, just visually, the sunflower is such a happy flower, and I must say I don't actually know why it's the Sunflower. I just like that it is. I really like the Sunflower lanyard as a way to communicate that. Where is this thought going? See, this is the... There are 60 thoughts running in my brain, and I'm trying to catch on to one.

Chantal Boyle:

Yeah. Yeah, and trying to grab onto one.

Jen Hankin:

Yeah. It just slipped away. When people aren't used to looking out for less visible disabilities, it can be very hard to identify this person is disabled and this person is not disabled. It's nice to have an option, a visual indication that perhaps you need to treat me more gently than the average person. I know that, I would really like to see the awareness of the Sunflower lanyard increase in Australia. A lot of people don't know what it means unless they're in the know at least in my area, but I hope by wearing it out and having those conversations that I can start to make it a thing.

Chantal Boyle:

Start raise awareness.

Jen Hankin:

Yeah, raise awareness and make it a thing.

Chantal Boyle:

What would you say to Australian businesses about becoming Sunflower friendly and joining the global network?

Jen Hankin:

By not having knowledge of the Sunflower lanyard, businesses are missing a valuable opportunity to either increase their inclusivity or start the process of becoming more inclusive. I know that, with LGBTQI-Plus Pride, there are a lot of businesses who now... They make it very clear that this is a friendly space. This is a safe space. We are the type of people who want you here. I would like to see that, but for people with disabilities. If they can do it for LGBTQI-Plus, they can certainly do it for disabled people.

Chantal Boyle:

I guess it brings us onto our final question of where can people find you if they're interested in your creative pursuits?

Sandee Facy:

Plural.

Jen Hankin:

I can be found in most places. I have a website, theemeraldruby.com.au. Is it .au? No. It's just theemeraldruby.com. I should know my own website. I'm on Facebook, Twitter, Instagram, YouTube, TikTok, although my most polished stuff isn't on TikTok. It's mostly me being like music is hard. Having a disability is hard. You can find my music in most places. If you want to listen to my music, it's on YouTube Music, Apple Music. Half of my music is on Spotify. I have a very complicated relationship with Spotify.

Speaker 1:

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Chantal Boyle:

That brings us to an end of our conversation today, Jen. Sandee and I think have both thoroughly enjoyed chatting with you and been very impressed but saddened how you

didn't get the support you needed early on with your education and, again, when you were doing your thesis. I guess, it shows, it's a testament to your perseverance that you have still been able to create a career and you are supporting other young people to also enjoy music. What particularly struck me was when you said you can have one bad experience and it can put you off music for life and I don't want that to ever happen to any student that I have. And it actually makes me feel quite emotional, you are doing a great job and thank you very much.

Jen Hankin:

Thanks so much for having me it's been a pleasure.

Speaker 1:

If you'd like to share your Sunflower story or conversation, please email conversations@hiddendisabilitiesstore.com. Find out more about us or listen to this recording again by checking out our insights page at hiddendisabilitiesstore.com. You can also find us on Facebook, Instagram, Twitter, YouTube and LinkedIn. Please help, have patience and show kindness to others, and join us again soon. Making the invisible visible with The Hidden Disabilities Sunflower.