

Intro: Choice and Control, a podcast celebrating people with disability. In this season we're talking about access, inclusion, and the National Disability Insurance Scheme. This podcast series is brought to you by Carers Queensland, NDIS Local Area Coordination Partner in the Community.

00:23 Jodie van de Wetering: Hi, I'm Jodie van de Wetering. Today I'm talking to Rebecca Johnson, a young artist from Rockhampton who's living with bipolar disorder and chronic illness. Despite it being a really rough year, Rebecca has come out on top with some answers about her health and some amazing achievements with her artwork, even the start of new business.

00:43 Rebecca Johnson: Originally, I was always interested in music. And so when that kind of became difficult with my physical health, I always found that when I was sick I would turn to making visual art because it's a lot quieter and not having to deal with, I guess, people watching while I'm doing it. And then that kind of turned into a way of expressing how was feeling with mental illness, and physical illness, and being able to portray how I'm feeling and what I'm thinking in a way that didn't require me to talk.

01:19 Jodie: Now Rebecca is sharing her voice and her vision with more people through her art. She's part of an exhibition run by Carers Queensland, we'll find out more about in just a moment, and she also has her artwork on the cover of a 2021 calendar.

01:32 Rebecca: It's by Art from the Margins which is based in Brisbane. They created the competition for people facing adversity. So it covered everything from mental illness, physical disability, to Indigenous people and people who are living in rural communities. So I entered it with two pieces that spoke about my relationship with my mother, and how she has always been the person that I can lean on and who can be there for me and comfort me when I'm struggling. One piece which is called *Mothers Embrace* won the Andrews Light Up award, and then my piece *Hold Me Mother Before I Disappear*, which was lucky enough to be on the cover of their calendar for 2021 and be a part of that with 11 other great artists.

02:27 Jodie: How exciting, how did that feel when you found out you were going to be on the cover?

02:31 Rebecca: Probably a bit surreal. It was really exciting and a bit nerve wracking. I guess most of all felt really validating, in that what are making is something that doesn't just hold value to me, but to other people,

02:49 Jodie: Rebecca also has a piece in the This Is Me art exhibition run by Carers Queensland. It's a celebration of the achievements and talents of people with disability, from professional artists, right through the work from kids. It's a touring exhibition and we've just delivered it to the Banana Shire Regional Art Gallery in Biloela, where it's going to be on show until early March. Rebecca's

even sold the piece that she had involved in the exhibition: a realistic depiction of three salmon called *Even In Death*.

03:18 Rebecca: Yes, my father had caught three fish and taken a photo of them for me to paint. I painted it without knowing why, but just that I felt very drawn to it, and came up with the idea afterwards that it was about life and death and the death of the person that I was before I was diagnosed with chronic illness and mental illness and has allowed me to, I guess, mourn than the person that I was through drawing something that is probably a bit morbid, but it's going through the same life-death cycle. Yeah.

04:08 Jodie: That's how it felt? It felt like a grieving, like a loss, that process of getting diagnosed?

4:14 Rebecca: Yes. I spent a long time, well, through all of my teenage years, going to doctors and trying to work out what's wrong. And because I was never given a definitive answer - I was given the diagnosis of chronic fatigue syndrome, which is a diagnosis by exclusion - so it was never really a definitive 'this is what you have'. So it took me years and years of learning that I've lost the person who I was, in regards to my physicality and being able to move and just do things, walk, shower unassisted. Realising that I've lost that part of me. But now there's the birth of something new and a new way of living, trying to learn, to accept my situation, opens up a

whole world of different ways I can try to help myself with accessibility and learning how to live again in a new way.

05:26 Jodie: One of the things that came up when I was speaking to Barb Cook, who is a lady diagnosed well into adulthood with autism, was that in finally getting the diagnosis she found the answers, and the community, and things starting to make sense. But was that a bit unsatisfying that you didn't really have those answers yet?

05:45 Rebecca: Incredibly. It was really hard, you know, seven or eight years of just feeling like all the pieces aren't in place. Knowing that there's something wrong with me, but the medical community saying 'you'll grow out of it' or 'all teenage girls have low blood pressure'. So, you know, just cause you're passing out, that's fine, if it happens a few more times, then we'll worry. It's just being told that you're not sick enough, it's not sick enough to worry about. And yet I was still not able to go to school and not able to live a so-called normal life.

06:31 Jodie: Where are you at now? Do you feel like you've got the answers now or is it still feeling a bit vague?

06:37 Rebecca: I think we finally worked it all out. It took about five years with the diagnosis of chronic fatigue to then realise that this whole time I've been having irritable bowel syndrome quite severely, which is obviously impacting the fatigue side of things. And then this year, the diagnosis of bipolar disorder, I guess, tied it all together and

I realised also how much of a connection there is between the brain and the gut and fatigue. Hopefully now working on all parts of it, isolated, that it can start to feel a little bit more calm.

07:22 Jodie: And has expressing yourself through art or through music, through craft, has that helped as you've been going through that journey?

07:31 Rebecca: I think it was the only thing that kept me going, feeling like I had something to put my energy and my thoughts and especially my feelings into, made it feel like if I had something that came out of it, that was good. Made me feel like it was worth the struggle and worth going through the pain, especially the emotional pain that I have been having with the bipolar, it made it feel like even though this is something really hard and I don't want to handle it, at least I'm getting something creative out of it in the end.

08:09 Jodie: If you're late-diagnosed or you acquire a disability later in life, that can bring a need to reevaluate who you are and what that means for you. It can also mean unpicking a lot of internalised ableism: negative ideas about disability you might have unconsciously picked up, even if you have disability yourself.

08:27 Rebecca: I still struggle with the idea of identifying as disabled, because I feel like that's offensive to people with more visible disabilities. But then I acknowledge that other people with invisible disabilities, it's just as important for them to have a

community and to be able to identify as that. So kind of gatekeeping myself, and listening to other people that say 'you're not sick enough' or 'you're not disabled enough to be able to identify as something'. It's just working through that. And I still have a lot of internalised ableism about, it's taken a long time for me to let myself use disability aids, because I just thought that I should be able to behave like every other healthy person, you'll be all right, it's not that bad.

09:21 Jodie: And there is a lot of unlearning in there and you think, you might intellectually know it, but you don't emotionally understand it yet. I was well into my thirties when I suddenly had the revelation that not being able to stand on one leg isn't a moral failing on my part. Which sounds ridiculous, but it was something I genuinely felt quite ashamed of. So there is the most ridiculous little bits of internalised ableism and it does take a long time to unpick that.

09:48 Jodie: Yeah, I've got a long way to go, but it's just learning, you know? It's okay if I can't stand up to shower, that's okay. And just because I have a fluctuating illness and disability, that doesn't mean that it's fake or not real or all in my head. And I think for a lot of other people watching, if I can get up on stage and perform one week and then be really debilitated and sick in bed the next, that they think it's not real, or I'm not sick enough, but it is real.

We are very mean to ourselves. And especially if doctors or family or friends have said those things to you, about you not being sick enough, or 'at least you're not in a wheelchair' which is a whole other horrible thing. How would somebody in a wheelchair feel about you comparing, you know, going 'oh, well, that's the worst case scenario'. How would they feel? I think there's a lot of learning to do and a lot of unlearning to do.

10:59 Jodie: Where would you like to go from here? So your idea is to head back to study next year, you're working on a Diploma of Visual Art. Do you have a plan, or is it a 'take one day at a time' situation at the moment?

11:12 Rebecca: Hmm, it's funny because I used to be the kind of person, like when I was 12, where I planned everything. By the time I was 12 I'd planned what my formal dress was going to be, and that I was going to go to NIDA, and I tried to work out all the expenses when I was 12, working out the expenses of living in Sydney.

And then that kind of all got blown out and I realised, it's taken a really long time, but I realised that it's sometimes important just to live day by day. I have a few things that are goals, and I would love to do a few market stalls in the new year and I'd love to enter a few art competitions. But if I don't, if I'm physically or mentally unable to meet those deadlines, there's always another opportunity.

12:08 Jodie: Speaking of the market stalls, this is really keen because not only is it a means of creating something, but then actually potentially having a product and it can become a business in itself. So could you tell us a bit about Tutti Frutti Handmade?

12:20 Rebecca: My Mum and I decided that we would work together to create some products, especially around crochet, when she had to leave work to look after me. I've gradually become steadier with my health and so able to work together on creating things and coming up with designs. I had always had a dream of making earrings like Luna from *Harry Potter*. First tried when I was 13, and now finally, by the time I'm 20, I managed to make a pair of not radishes, but strawberries. Then, wearing them around and expressing myself through some quirky accessories, I realised there were a lot of other people that really enjoyed them too. So hopefully working together and helping each other out, we'll be able to, grow as a business and as a personal relationship.

13:23 Jodie: And markets are great in that you can go when you're well, and when you have the energy, you haven't got a shopfront, you haven't committed to being available eight til five, five days a week. You can, to some extent plan around your health?

13:39 Rebecca: Yeah, definitely. And if on the day I'm really unwell, I can always look to my sister or my Mum or my boyfriend to be able to actually man the stall for me. And it's taken a bit of prior planning

and starting a month in advance of making things to make sure. I've had a few bouts of migraines and things. So try to work around that and know that if I got started early on, that even when I had issues come up that there'll still be a lot of progress made.

14:12 Jodie: How important has it been to have that community around you too? Particularly your Mum, by the sound of it she's been really important.

14:18 Rebecca: It's been really good. I don't know where I would be without, without those people, my family and my boyfriend.

Especially meeting my boyfriend when I was in a manic episode, and didn't know because I didn't have my diagnosis yet, and having that relationship and getting the diagnosis while we were together and him staying with me and working things out with me. That's been a really important relationship, to know that I was lovable before this diagnosis and I still am lovable with the diagnosis.

There's a YouTuber, Jessica Kellgren-Fozard, who talks about her wife being constantly referred to as a saint for being with her, and how negative that is and how that continues to perpetuate the ableism and the idea that for somebody to be with someone with a disability, they must be just beyond human, because it must just be so hard. But really, they're just two people that appreciate each other and love each other. And that's a beautiful thing.

15:34 Outro: Thanks for joining us at Choice and Control, a Carers Queensland podcast. For more information about Carers Queensland, the National Disability Insurance Scheme, or the Local Area Coordination Program, please contact us online at www.carersqld.com.au.

Or you can catch up with us on [Facebook](#), search for 'Carers Queensland NDIS'.

This podcast is a place for people with disability to share experiences, stories, and achievements. If you have a story you think we should know about, please contact us through the Carers Queensland inquiries line on 1300 999 636, or email cq.enquiries@ndis.gov.au.

Until next time, thanks for listening.