



Narcolepsy Perspectives: A blog about anything & everything Narcolepsy

Narcolepsy and Mental Health Discussion with Cory Skuza and Tre Burge

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April 8, 2024 - Hello and welcome back to Narcolepsy Perspectives!

Last time we discussed support groups and how they can be beneficial for people with Narcolepsy. I, for one, have experience participating in and volunteering as a facilitator for Wake Up Narcolepsy's support groups. As a writer and artist with Narcolepsy, I have found support groups to be vital for my mental and physical wellbeing. Support groups are a great reminder that we are not alone in our struggles, and they help keep me on track with shamelessly setting boundaries when it comes to living with my condition.

Mental health is an especially important topic for the Narcolepsy community. In "[Conditions You May Have Along With Narcolepsy](#)," Kathleen Fordyce states "People with narcolepsy often have overlapping mental health disorders, such as depression and anxiety." It isn't clear why these comorbidities are linked with Narcolepsy, but what is clear is this - we are not alone in our mental health struggles! One of the most important things we can do to dispel the shame that might come along with mental health struggles is by sharing with safe people who understand what we are going through. I recently had the pleasure of discussing mental health with two people with Narcolepsy, Cory Skuza and Tre Burge. Our conversation is as follows:

How has Narcolepsy impacted your mental health?

Cory: Before I was diagnosed my mental state wasn't great and management was incredibly difficult. I wouldn't have any resemblance of order in my life at all. Trying to hold anything together was about as hard as painting snow with water.

Tre: Narcolepsy has impacted my life in several ways. For instance, not getting sufficient sleep at night results in an increase in anxious behaviors.

Tatiana: It was quite a shock to me when I developed Narcolepsy in college. At the time I was an honors student working as a research assistant in the university lab. I was planning on going to medical school. Suddenly I wasn't able to do what I thought I was supposed to be doing because of the severity of my symptoms. It broke my heart. And it almost broke me.



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What kind of stigmas do you run into?

Cory: The amount of people who think I'm drunk or on drugs, while I'm fighting a sleep attack. Or one time my wife's dad was insulted when I took a nap on the couch. LAZY! Unmotivated, mooch, good for nothing. Those are just my thoughts, I'm sure others would say the same if it wasn't rude to do so.

Tatiana: I second what Cory said. I've actually lost friends who assumed that I was on drugs causing my severe Narcolepsy symptoms, or somehow otherwise causing them. I've been harassed in public and almost had security called on me for having a sleep attack in public. A lot of people just don't listen or care when it comes to invisible disabilities. To think that I would willingly suffer like this is insulting and hurtful.

Tre: I didn't believe that I had depression in the past. Instead, I thought there were things happening outside of my control that were making me sad.

Have you had any mental health treatments available to you?

Cory: My whole life I've been in and out of therapists and seen plenty of psychiatrists. The treatment was everything you'd expect - but nothing to help sleepiness.

Tatiana: I started really getting access to mental health treatment after my Narcolepsy symptoms developed. One of the most helpful resources I utilized was art therapy. It was a way for me to channel my pain into something beautiful. Even though I'd fall asleep during art therapy, I could wake up and continue painting until the piece was finished. It was empowering and provided structure to my otherwise (newly) empty days. Talk therapy is something that I participate in multiple times a month. It helps keep me on track and challenge the unhealthy thought patterns and behaviors that I live with. It takes a lot of work to change the way my brain works. But over time I have noticed vast improvements. Although my depression and anxiety still gets just as bad as it used to, I now have an arsenal of tools at my disposal to combat them.

Tre: I have, the treatments did help.

How have Narcolepsy treatments affected your mental health?

Cory: Treatments are so frustrating but can be so effective, once you find what works for you, of course. CPAP, medications, and a strict sleep schedule has been what works for me



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so far. But as for the mental health, it's all connected. A bad Narcolepsy day will make a bad depression day, and vice-versa.

Tatiana: Adequate Narcolepsy treatments definitely improved my mental health! Poor Narcolepsy treatments made my mental health so much worse. For example, certain stimulants make my anxiety so much worse. And sodium oxybate made my depression almost unlivable. Once I found the right Narcolepsy treatment plan for me, my quality of life improved. I'm not "fixed" by any means - but I am more stable now.

Tre: So I'm currently not taking anything for my Narcolepsy right now. It's very difficult. When I was on treatments my mental health was better.

What are some of the best mental health coping techniques you use as a person with Narcolepsy?

Cory: Strict sleep hygiene is a number one. Then I'd say art helps with those bad days. If it feels like I can't do anything or I feel worthless, I'll draw something. It doesn't require a ton of effort and I try to have a pencil and paper, mostly post-it's, within reaching distance at all times.

Tatiana: Like Cory said, making art is a huge one for me. Getting out into nature is another coping skill that helps, but isn't always possible when you're scared of falling asleep alone in public. But art is always accessible. I also channel my feelings into poetry and other writing projects, such as my gothic fantasy novel about an ex-scientist with Narcolepsy (sound familiar?)

Thank you Cory and Tre for being willing and open to sharing your experiences with Narcolepsy and mental health! It isn't an easy subject to talk about, and I appreciate you opening your hearts to us.

It is my hope that as we open up these kinds of discussions, we can decrease any stigma associated with it. I just want people to know that they are not alone! There is help out there for us.

The bad news is that living with Narcolepsy can negatively impact our mental health for a variety of reasons. The good news is that there are many mental health resources available for those living with Narcolepsy.



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Wake Up Narcolepsy provides free online support groups for people with Narcolepsy. I have found these support groups to be essential to my mental health. There is nothing more powerful than feeling supported and encouraged by other people who can relate to what we are going through!

You can find mental health resources, including information on support groups, from Wake Up Narcolepsy [here](#).

There are also mental health resources available specifically for teens with Narcolepsy. More information on these resources can be found [here](#).

References:

Fordyce K. What are comorbid conditions for narcolepsy? WebMD.
<https://www.webmd.com/sleep-disorders/conditions-with-narcolepsy>.