



NARCOLEPSY & BRAIN FOG TOOLKIT



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WELCOME!

We are so glad you are here. This toolkit is designed for people living with narcolepsy and their loved ones to offer new tools, tips, and perspectives on navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

Narcolepsy Nerd Alert is an educational series diving deeper into specific topics relevant to narcolepsy. Each month, Project Sleep broadcasts a live event via Facebook, hosted by Julie Flygare, JD, Project Sleep's President & CEO.

After each live broadcast, we create a corresponding toolkit (like this one!) to capture our collective knowledge to help others down the road. Quotations featured in speech bubbles throughout toolkit are from participants who joined us for the live broadcast.

PLEASE NOTE

The Narcolepsy Nerd Alert series is intended for educational and awareness purposes and is not a substitute for medical attention. If anything in this toolkit sparks questions for you about your medical management, please bring those questions to your sleep doctor or narcolepsy specialist.



NARCOLEPSY & BRAIN FOG

Have you ever had issues with memory or thinking clearly?

On March 31, 2021, Project Sleep hosted the “Narcolepsy and Brain Fog” event to discuss what brain fog means to narcolepsy community members and how to better manage it. This toolkit compiles highlights and insights generated from this discussion.

- Watch the [Narcolepsy & Brain Fog](#) video
- Learn more about [Narcolepsy Nerd Alert Series](#)



WHAT DOES "BRAIN FOG" OR MENTAL FOGGINESS MEAN TO YOU?



MEET THE PANELISTS

Two featured panelists joined our host, Julie, to talk about brain fog, automatic behavior, and micro-sleeps, and how we can better manage these symptoms.



SHANNON BURKOTH

Shannon Burkoth has a background in business and healthcare and lives in Wisconsin with her family. Shannon was diagnosed with Narcolepsy Type 1 in 2010. She has been a trained speaker with the Rising Voices of Narcolepsy program since 2017, and advocates for both narcolepsy and rare disease. Shannon also works part-time for CLOVES Syndrome Community. Her passion is to raise awareness for this misunderstood neurological condition so that others may find a diagnosis and treatment as soon as possible.



DR. KIRAN MASKI

Dr. Kiran Maski is an expert in pediatric sleep neurology, and a sleep medicine physician at Boston Children's Hospital, specializing in narcolepsy and sleep problems of children. She is also a sleep researcher, and her work on improving the diagnosis of narcolepsy has been published in SLEEP, the official journal of the Sleep Research Society.



NARCOLEPSY SYMPTOMS

These are currently considered the five major symptoms of narcolepsy:

- Excessive daytime sleepiness
- Cataplexy
- Hypnagogic and hypnopompic hallucinations
- Sleep paralysis
- Disrupted nighttime sleep

These are some other symptoms commonly described by people with narcolepsy:

- Brain fog/mental fogginess
- Automatic behavior
- Micro-sleeps
- Mood instability

SHOULD BRAIN FOG BE ADDED TO THE NARCOLEPSY MAJOR SYMPTOMS LIST?

- It is unclear whether brain fog should be added to the major symptoms list or considered a very common comorbidity.
- Recently there has been a shift in how researchers view brain fog, and according to Dr. Maski, clinicians are beginning to say, "This is a neurologic process. This is a real debilitating symptom, not just, 'I went to bed late and feel a little foggy today.'"



BRAIN FOG OR MENTAL FOGGINESS

Cognitive functioning issues such as difficulty thinking, remembering, concentrating, or paying attention

"Brain fog for me is a thick head behind the eyes, limited processing ability."

- Nick

- Dr. Maski says, "I've had people say it feels like something's physically on their head or that it's almost like cotton is in their brain and it just takes a lot of effort to speak."

"Brain fog for me has been using all of the mental capacity I have to focus on what I'm doing, only to realize that I have no memory of the past five minutes."

- Richelle



ARTWORK BY JOHNSON TSANG

"Since I was young I never felt like I had a voice because it was hard for me to remember and then articulate."

- Allison



"I find the fogginess from being in a half-sleep state during my limited waking hours is maddening. The fogginess causes me to forget conversations or commitments that I have made... People have decided that I'm unreliable, ignoring them or not honoring my commitments that I've made to them."

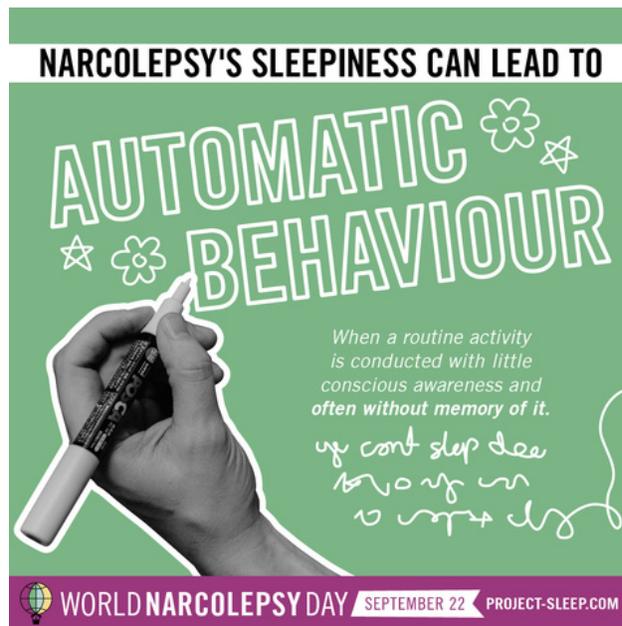
JOSEPH POPLAWSKI
NARCOLEPSY FDA MEETING, 2013



AUTOMATIC BEHAVIOR

Continuation of a routine activity with little conscious awareness and often without memory of it

- Julie says, "The example that comes to mind for me is taking notes in class, and then looking back later at the notes and seeing that they'd gotten messy and not quite legible."



"Automatic behavior is my biggest struggle."

- Hot Nerd Club

- This infographic, created by Elle Wales for World Narcolepsy Day 2020, was shared widely and resonated with many community members.

- Shannon says, "I've poured orange juice into my cereal instead of my glass because I was just going through the motions and not realizing what I had in my hand."

"I often find [automatic behavior] happens when I eat something and the next minute it's gone and I'm still hungry and have little memory of eating it."

- Leah



MICRO-SLEEPS

Periods of memory lapse or blackouts caused by very short periods of sleep

"I used to have micro-sleeps in conversations and start talking about complete nonsense."

- Shannon

- Dr. Maski says, 'With both automatic behavior and micro-sleeps, there just hasn't been a lot of research on these specific symptoms. [Our current understanding] is based on patients' descriptions of what happens.'
 - She explained that what's probably happening is that people fall asleep for a very short time and are able to wake themselves up, but this is not refreshing or intended.
- Julie added that micro-sleeps and automatic behavior are more likely to happen when she knows she's tired and is trying to fight through it.



ARTWORK BY AYKUT AYDOGDU

"It feels like parts of REM sleep can happen during the day. I remember straining my eyes in lecture, trying to make sense of what's on the white board, and feeling a micro-sleep coming on: the teacher's voice would go away and my eyeballs would literally shake from left to right rapidly, while open."

- Taylor



MOOD INSTABILITY

Moodiness, irritability, less positive mood, internalization, aggressiveness, hyperactivity or impulsivity

- Community members expressed that frustration with brain fog can lead to mood instability.

"I totally feel that moodiness due to frustration with the brain fog and sleepiness."

- Kelley



ARTWORK BY JOHNSON TSANG

- Dr. Maski says, "This is something that I think we hear about a lot from parents of pediatric patients with narcolepsy; how moody their children are towards the end of the day, or they pick fights with their siblings or friends. In rare cases we even see aggression happen. It seems like the kids really regret the behaviors. They feel better after they sleep, but I think it's probably a manifestation of that sleepiness."
- Shannon says, "Any person who goes without sleep is going to be moody."
 - She also suggested using a code word with family members to indicate when you just need to take a break, and you're having trouble communicating.



"Brain fog makes me feel like I have a social disorder. People try to make small talk at work and sometimes I literally cannot respond. I just pretend I didn't hear them and I feel so rude."

- HELEN



EXCESSIVE DAYTIME SLEEPINESS

Periods of extreme sleepiness during the day that feel comparable to how someone without narcolepsy would feel after staying awake for 48 to 72 hours

Excessive daytime sleepiness is one of the five major symptoms of narcolepsy. Is brain fog related to sleepiness or something else?

- **Feeling sleepy vs. inability to stay awake**

- There is an important distinction between sleepiness and falling asleep: sometimes you might be able to fight though and stay awake, but may not remember what happened or what was said.

"I can force myself to stay awake, I just can't function."
- Michael



ARTWORK BY AYKUT AYDOGDU

- Julie says, "I wonder sometimes if when we think of sleepiness as just falling asleep, we're missing a huge gray area, which is the gap between being feeling fully awake and cognitively functioning well, and being asleep."
- Dr. Maski asks, "Why don't we have a system of 'staging' for wakefulness" like the stages of sleep?"



CURRENT RESEARCH

While brain fog or mental fogginess is a challenge faced by many people with narcolepsy, it hasn't always been recognized or talked about. Research within the past decade has begun to explore the impacts and causes of brain fog in people with narcolepsy.

- In 2013 the FDA held a Patient Focused Drug Development meeting, specifically for people with narcolepsy, and published a report titled "[The Voice of the Patient](#)".
- Mental fogginess or brain fog was cited by numerous patients even though it was **not** listed in the [FDA's polling question](#) about most impactful symptoms.
- Following this meeting, a survey gave people with narcolepsy the opportunity to describe their experiences, and a report titled "[Listening to the Patient Voice in Narcolepsy](#)" was published in the *Journal of Clinical Sleep Medicine*.
- Dr. Maski and other sleep researchers are investigating some of the big questions around brain fog that emerged from responses to the survey.

"I think [the responses about brain fog] are striking because it goes to show, possibly, that this is something important to patients that's not being talked about a lot."

- Julie

"Our work is inspired by the patients and for the patients, so we really appreciate all the support we get from Project Sleep and from the patients themselves."

- Dr. Maski



CURRENT RESEARCH

Dr. Maski and others are seeking to understand whether there are connections between major symptoms of narcolepsy, such as disrupted nighttime sleep and excessive daytime sleepiness, and symptoms of brain fog.

IS BRAIN FOG RELATED TO DISRUPTED NIGHTTIME SLEEP?

- Dr. Maski says that narcolepsy and brain fog are probably related and that sleepiness may be what connects them.
- Disrupted nighttime sleep may be one factor contributing to brain fog, and there are other possibilities as to why people with narcolepsy may experience these symptoms. Other possible contributing factors include inflammation, immune mechanisms, or autonomic function.
- Dr. Maski's group is investigating if disrupted nighttime sleep, experienced by 50-90% of people with narcolepsy, could be a factor in the memory issues people experience.
- To assess how sleep affects memory, children and adults with narcolepsy are given a learning task and then asked to recall the information after a 10 hour period of either wake or sleep.
- The study is ongoing and Dr. Maski's group hopes to have conclusive results to share over the next year.
- Dr. Maski explains, "When a memory trace gets more stable, we call this consolidation. We call it sleep-dependent consolidation to really signify that **sleep is necessary for that process to occur.**"

"We're interested in this because there is a relationship between sleep and memory. There's over 40 years of data showing that sleep is really a necessary process for good memory function."

- Dr. Maski



"I find brain fog is the inability to process information. I find myself staring into space, at a screen or page for ages with no progress. I lose a lot of time in my day which can be frustrating and often means I fall behind at work or in my personal life."

- LEAH



MANAGING BRAIN FOG

Panelists and community members shared their insights and strategies for managing brain fog.

- Shannon sets alarms on her phone for every appointment or meeting.
- Note taking can help you recall what you heard or learned. In some situations, a recording device can be really helpful, as long as you have permission to record.
- Dr. Maski suggests standing desks or movement breaks, if possible.

"I've learned with brain fog it's best to do food prep or cooking early in the day to avoid accidents."

- Shannon

"I had never made the connection that my need to take notes and write everything down was related to my narcolepsy."

-Richelle

- Cognitive Behavioral Therapy (CBT) may help some narcolepsy patients to understand the condition and how to advocate for themselves and come up with behaviors that might be helpful for managing brain fog.

- For those who are not enthusiastic about napping, Dr. Maski says, "we oftentimes advocate quiet time" and suggests that lying down for 10-15 minutes can be enough to get you through a difficult time.

"If you are offered accommodations, take them, they are there for the day you need them."

- Cassandra



COMMUNICATING ABOUT BRAIN FOG

Panelists and community members shared their thoughts about describing the experience of brain fog.

HOW CAN WE BETTER COMMUNICATE ABOUT BRAIN FOG SYMPTOMS?

- **It can be difficult to describe the "gray area" between being fully conscious and fully asleep.**
 - Analogies can be helpful in this area, if they accurately represent the experience. Julie says, "The analogy that worries me is thinking of sleep as a switch because it sounds as if being awake or being asleep is just on and off, when to me it's more like a strobe light."

"With brain fog, the most frustrating part for me is being in the middle of it, the restricted feeling and not being able to explain why or what's happening."

- Cassandra

"It feels like my brain goes somewhere without me."

- Dayja



ARTWORK BY AYKUT AYDOGDU

- **Poetry and art are powerful ways to communicate about these experiences.**

"It's like I'm reading a teleprompter and the words just stop on the prompt."

- Greg

BRAIN FOG

Open the door, like I did once
before.

Nothing's new or has changed,
just the thoughts in my brain.

I'm confused, let's rewind, lost my
moment in time.

Will I finish my tasks, while my mind
feels detached?

- ANA E. LARA



RESOURCES

Here are resources discussed in the toolkit and some of our other favorites. We look forward to hearing what our fellow #NarcolepsyNerds find most useful for navigating narcolepsy!

PATIENT ORGANIZATIONS

- Major US Organizations:
 - [Hypersomnia Foundation](#)
 - [Narcolepsy Network](#)
 - [Project Sleep](#)
 - [Wake Up Narcolepsy](#)
- International Organizations:
 - Listed on Project Sleep's [World Narcolepsy Day webpage](#)

ARTICLES

- ["The Voice of the Patient: Narcolepsy"](#)
U.S. Food and Drug Administration/Center for Drug Evaluation and Research. (2014). *The Voice of the Patient: Narcolepsy Summary Report*.
- ["Listening to the Patient Voice in Narcolepsy"](#)
Maski K, Steinhart E, Williams D, Scammell T, Flygare J, McCleary K, Go M. *Listening to the Patient Voice in Narcolepsy: Diagnostic Delay, Disease Burden, and Treatment Efficacy*. J Clin Sleep Med. 2017 Mar 15;13(3):419-425. doi: 10.5664/jcsm.6494. PMID: 27923434; PMCID: PMC5337589
- Julie Flygare, [Narcolepsy Isn't Like the Movies: 16 Secret Signs of Daytime Sleepiness](#)

FEATURED ARTISTS

- [Aykut Aydogdu](#)
- [Johnson Tsang](#)



THANK YOU!

We are so grateful that you took the time to check out this toolkit!

Project Sleep is a 501(c)(3) nonprofit organization dedicated to raising awareness about sleep health and sleep disorders.

More resources at: www.project-sleep.com

