

NARCOLEPSY + ART 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. For each episode, 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. Quotes featured throughout the toolkit are from panelists and participants who joined us for the live broadcast. Narcolepsy Nerd Alert videos and podcasts are also available via our website, YouTube, and wherever you listen.

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 + ART

What's your creative outlet?

On Feb 28, 2023 Project Sleep hosted the "Narcolepsy and Art" live broadcast with an incredible panel of artists from around the world. They shared their work and gave us a rare glimpse into the creative process.

Panelists discussed the relationship between creative expression and living with narcolepsy, gave advice for aspiring artists, and answered questions from the community.

This toolkit is a compilation of insights from the artists and the pieces they shared during the broadcast.

- Watch the "Narcolepsy and Art" video: <https://youtu.be/e4Y5dQgqj0>
- Learn more about the Narcolepsy Nerd Alert Series: <https://project-sleep.com/narcolepsy-nerd-alert/>



MEET THE HOST

Julie Flygare, JD, currently serves as President & CEO of [Project Sleep](#). She was diagnosed with narcolepsy with cataplexy in 2007 while in law school. Julie is an internationally recognized patient-perspective leader, an accomplished advocate, and the award-winning author of *Wide Awake and Dreaming: A Memoir of Narcolepsy*.



SOLOMON BRIGGS



Solomon is a patient advocate, author, and artist. He is also a skateboarder, snowboarder, ice hockey player, and cook. His art expresses the difficulty and complexity of living with invisible medical conditions.

In this piece, titled "**Heavy Head,**" Solomon used acrylic paints to portray both excessive daytime sleepiness and mild or moderate cataplexy.



He says, "My art is directly inspired by broken sleep. I try hard to express actual elements of living with difficult, complex, rare, and invisible diseases."

Solomon has published several books about his life with type 1 narcolepsy and other invisible illnesses, which are available on Amazon. This painting is the cover art for Solomon's book, *DIS*.



JONATHAN CORREA



Jonathan is a photography hobbyist and outdoor enthusiast. He was diagnosed with narcolepsy in 2014, more than ten years after his initial symptoms. Jonathan is a lifelong resident of the Shenandoah Valley in Virginia.

The piece is called ***Dream Lake***. The black and white photo shows dimly lit stalactites, reflected in a still pool of water.



Jonathan took this photo at a feature called Dream Lake in Luray Caverns, Virginia on World Narcolepsy Day 2021. He says, "I didn't know, in such a low light situation how it was going to turn out. And with film you don't have any way of knowing until you develop it... I'm pretty pleased with it."



SILENCE HANDS



Silence is a mother of two and a multi-disciplinary artist from Tennessee. She was diagnosed with type 1 narcolepsy with cataplexy at age 35. As a speaker with Project Sleep's Rising Voices program, she hopes to improve awareness of narcolepsy and to undo misconceptions of this neurological condition.

This is the first piece in a series that intentionally involves narcolepsy. In the photo Silence is in her kitchen, holding a sculpture made of medication packaging that is painted yellow like the sun. Silence shared, "Usually for me creating a piece is very playful. I like to make a lot of revisions."





DANA HAREL



Dana lives in Israel with her husband and two children. She is a developmental psychologist and artist. She was diagnosed with type 1 narcolepsy with cataplexy at age 34 after living with symptoms since she was 18. Her artwork primarily involves paper craft, scrapbooking, and mixed media.

This piece represents the two types of narcolepsy: type 1 narcolepsy with cataplexy, and type 2 narcolepsy without cataplexy. On the left Dana shows cataplexy and the other symptoms related to REM stage sleep, and on the right side, boredom and the complex relationship of sleep and wakefulness. Dana says, "Contrary to the demands of reality, there are no rules in art."





SHU HORIIKE



Shu lives in Japan and is a freelance designer, web engineer, and digital art director. He creates glitch art using digital photography, his own effort, and apps like Glitché and others. Shu is a member of the Japan Narcolepsy Association and hopes to use his art to raise awareness of narcolepsy in Japan.

Shu's work expresses the specific feelings of narcolepsy and hypersomnia. This piece represents fear of memories being sliced out. It also expresses the anxiety of shaking vision, distorted sounds, and feeling uncomfortable under the gaze of others.



Shu says, "I feel that the malfunction caused by this disruption of electrical signals, which was a common abnormality in old machines, is very similar to my narcolepsy."



ULRIKE NORDQUIST



Ulrike is a painter and photographer living in Sweden. She is a mom of two, and developed narcolepsy at age 38 after many years of misdiagnosis. She is now a speaker with Rising Voices, and shares her story to shed light for others coping with narcolepsy. Ulrike shared a piece called *My Beautiful Nightmares* from her collection, *30 States Photographies*, which covers the borderline between dream and reality.



Ulrike created this collection in response to the question, "How would you interpret a border or borderline?" She says, "As you might guess, it's a project on hypnagogic hallucinations and sleep paralysis. I immediately visualized this borderline between dream and reality, sleep and wakefulness, and it was completely clear. I had the whole project done in my head in one day."

She collected materials from her local community, and built sculptures that were "uneasy but also beautiful" with wooden hands, makeup dolls, and masks. Finally she photographed the sculptures and printed the images on aluminum sheets.



JAYDEN ROWLAND



Jayden is an art major at Oklahoma Community College who was diagnosed with type 1 narcolepsy with cataplexy at age 15, and has been raising awareness ever since. As an artist and speaker with Project Sleep's Rising voices program, Jaden conveys the struggles of not being taken seriously, achieving a diagnosis, and their ongoing battle with depression and self-acceptance.



Jayden shared, "When I developed narcolepsy at age 15, my art became more than a talent; it became an outlet for self-expression. I'm in college right now, and this particular comic showcases a lot of the struggles that can happen day-to-day."

Jayden is inspired by Studio Ghibli, and hopes to eventually create a graphic novel and an animated film portraying a character with narcolepsy.



ADVICE FOR ARTISTS

“Get rid of your expectations. Don't try to make everything perfect.” -Silence

“You can make an impact in this fight because of your condition... When you have dreams and the dreams are shattered, then you have to find new dreams.” -Ulrike

“Stay true to your passions.” -Jayden

“Any hobby can be expensive, but there are always options like second-hand equipment and rentals. You don't have to have the newest stuff to get started and express yourself.” -Jonathan

“Everyone can find their artistic side—whether you have a lot of experience in art or whether you have never held a brush in your hand.” -Dana

“Any artwork has *something* we have to or want to say. We have to keep searching for that ‘something.’” -Shu

“Practice and inspiration are key... Have fun with it! If it's burdening or stressful, change things up.” -Solomon

“Collect information on how other artists are making a living. Do they have additional sources of income? What work experience do they have? What other types of financial support are available? So that you can realistically support yourself while living a creative life.” -Ulrike



RESOURCES

See more of the panelists' artwork and advocacy on their Instagram pages.

- Shu Horiike: @shu_2h3
- Ulrike Nordquist: @ulrike_nordquist_art
- Silence Hands: @silencehands
- Jonathan Correa: @loosekwjibo
- Jayden Rowland: @dreaminginstarlightx
- Dana Harel: @dana_harel8
- Solomon Briggs: @narcoplexic

ARTIST PERSPECTIVES

Artist Profile and Workshop with Tatiana Corbitt. Paint with and learn about Tatiana Maria Corbitt, a writer and multidisciplinary artist and person with narcolepsy living in the Pacific Northwest: <https://www.youtube.com/watch?v=dRYKZYrrla0&t=8s>

Briggs, S. (2023) *DIS: RAISING AWARENESS Towards DISorders of Sleep With a Deep-Dive-Focus into Type 1 Narcolepsy*. <https://www.amazon.com/DIS-AWARENESS-DISorders-Deep-Dive-Focus-Narcolepsy/dp/0989991962>

PATIENT ORGANIZATIONS

- **Hypersomnia Foundation** www.hypersomniafoundation.org
- **Narcolepsy Network** www.narcolepsynetwork.org
- **Project Sleep** www.project-sleep.com
- **Wake Up Narcolepsy** www.wakeupnarcolepsy.org

International Organizations:

- Listed on Project Sleep's **World Narcolepsy Day webpage** www.project-sleep.com/worldnarcolepsyday.



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

