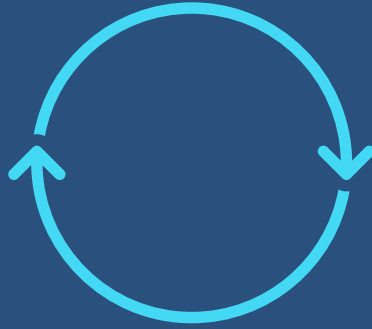




# NARCOLEPSY AND NAPPING



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Created by:

projectsleep



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# WELCOME!

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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. Quotes featured throughout the toolkit are from panelists and audience members who joined us for the live broadcast.

## PLEASE NOTE

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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 AND NAPPING

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## Got "nap shame?"

Napping can be both an unwelcome symptom of narcolepsy and a helpful treatment. On June 30th, 2021 we hosted the "Narcolepsy and Napping" live event. This toolkit is a compilation of insights shared by featured panelists Dr. Luis E. Ortiz and Mary Murray, host Julie Flygare, and community members from around the world.

- Watch the [Narcolepsy and Napping video](#)
- Learn more about the [Narcolepsy Nerd Alert series](#)



**IS NAPPING AN UNWELCOME SYMPTOM OF NARCOLEPSY OR A HELPFUL TREATMENT?**



**HOW DO YOU MAKE SPACE (MENTALLY AND LOGISTICALLY) FOR NAPS IN YOUR LIFE?**



# MEET OUR GUESTS & HOST

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Two special guests joined our host, Julie Flygare, to talk about napping as both a symptom and a treatment.



**Luis E. Ortiz, MD** is a pediatric sleep specialist at Johns Hopkins All Children's Hospital in St. Petersburg, Florida. Living with narcolepsy himself, Dr. Ortiz offers invaluable insights from both a medical perspective and first-hand lived experience.

"Napping is part of the way we live our best lives. You're going to have a more interesting and varied life if you DO take the nap."



**Mary Murray** is a teacher, mother, avid reader, and lover of travel living in Los Angeles, CA. She was diagnosed with idiopathic hypersomnia at the age of 36. As a Rising Voices of Narcolepsy advocate, she hopes to help others understand what it's really like to live with this rare disorder.

"There's a lot of stigma about napping. But it's really important, and it's a valid treatment and something we need to more regularly discuss."



## MEET THE HOST

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**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*.



"Take the nap before the nap takes you."

- MANY PEOPLE WITH NARCOLEPSY



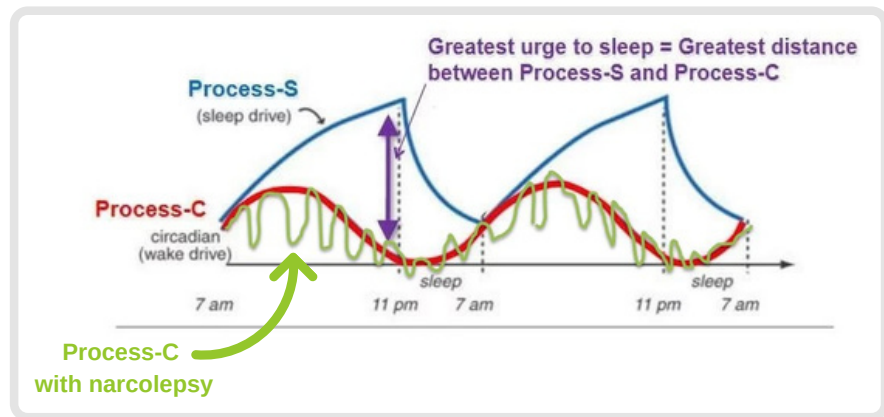
# THE SCIENCE OF NAPPING

“ I'm a sleep medicine doctor. I also have narcolepsy, so what I learned during my training really hits home. I feel it's really important to share why your sleep doctor may want you to take a nap. This comes from decades of research on what sleep is, what its purpose is, and how it works in our brain.

- Dr. Ortiz

Dr. Ortiz explained that sleep is driven by **two separate processes**, as shown in the figure below. **Process-S** is your sleep drive, which gets stronger the longer you go without sleep. **Process-C** is the circadian rhythm, which is your wake drive. In neurotypical brains, wake drive waxes and wanes over the course of the day, so after waking up it gets stronger, and at the end of the day it gets weaker.

With narcolepsy, it's not that the **Process-S** gets stronger, it's more that the **Process-C** drops out--it loses its intensity at inopportune times. This means that the greatest urge to sleep occurs several times throughout the day, instead of just at night.



- Napping improves alertness by diminishing the sleep drive.
- Taking 3 regularly scheduled 15 minute naps a day for a month was shown to improve daytime sleepiness.
- Alternatively, taking a prolonged nap (1-2 hours) about 12 hours from the middle of night time sleep can help reaction time and decrease unintentional napping.
- Drinking 1-2 cups of coffee and pulling over for a 20-minute nap has also been shown to temporarily increase alertness in drowsy drivers.
  - If you take an afternoon dose of stimulant, you can consider taking the medication before your nap (long or otherwise) to maximize alertness.



# WHERE TO NAP

It's not always easy to find a comfortable place to nap. Where do you nap at work or at school? Or at Disneyland?



JULIE IN WORK WELLNESS ROOM

“ I have a lightweight camping hammock that I sometimes use for lunch time naps.

- Richelle



MARY AT DISNEYLAND

- Having a **door that locks** can be very helpful. Instead of talking about going to take a nap, some people say they're going to meditate or do a little deep breathing, which can be more easily understood by people who do not have narcolepsy.

“ I'm so tired of coworkers saying, 'I wish I got to take a nap.'

- Elizabeth

- Dr. Ortiz keeps a pillow in a cabinet of his desk, and when he needs a nap he takes it out and sleeps on the floor. He also puts a sign on the door to his office that says, "**Do not enter. Do not knock.**"
- On a recent trip to Disneyland, Mary found a shaded nook when she needed a nap. She says, "I don't know how long I was asleep, probably about 15-20 minutes." My husband was there and he was watching our kids playing."

“ Going to a theme park is exhausting. It's tiring even for someone who doesn't have narcolepsy or idiopathic hypersomnia.

- Mary





# BEFORE NAPPING

Panelists and community members shared the insights that help them decide if and when they should take a nap.

- **Should we fight sleep or welcome it?**

Julie says, "Sometimes I can't tell if I'm having a small energy dip or a big energy dip. How do you figure out whether you should push through or 'turn down' your energy?"

- **FOMO (Fear Of Missing Out)** is a common reason people resist napping.

- **Scheduled or unscheduled naps?**

While studies show that scheduled naps may be more effective in managing daytime sleepiness, many people have to be more flexible with the timing.

“Fear of missing out is a big thing because we want to achieve as much as possible, even though that may be a little out of reach even without narcolepsy.

- Dr. Ortiz

“I wish I could schedule my naps because it would be more beneficial than waiting until I feel tired. It's just that my job is busy and I have to wait for a lull.

- Dr. Ortiz

“I often tell myself, 'If I was a smart man, I'd take a nap right now' and then I still try to truck along and end up wasting more time.

- Dr. Ortiz

“I try to tell myself when I am 'turning down' my energy that it's an investment in my future self for that day.

- Mary

“The hard part about napping is that it takes time. Even if it's just 20 minutes, when you look at the impact of taking 20 to 40 minutes or an hour out of a day, it's still a lot.

- Julie



# DURING NAPPING

Panelists and community members shared their experiences while napping.

- Many people with narcolepsy **feel anxious** about someone watching them or coming into their space while napping, and some people frequently hallucinate that someone is there while they nap.
- **Vivid dreams**--a key feature of narcolepsy--indicate a tendency to go into REM sleep, even during short naps.
- **How do you feel during a nap?**  
Like the painting below on the left, or like the sculpture on the right?

“ Sometimes I feel like it's taking me forever to fall asleep, when in reality I probably fell asleep right away.

- Mary

“ Having vivid dreams can make you feel like you never took a nap at all, because it feels indistinguishable from waking life.

- Dr. Ortiz

“ It can feel quite busy, like I didn't nap at all.

- Julie



FREDERIC LEIGHTON, FLAMING JUNE

OR



ARTWORK BY JOHNSON TSANG



# AFTER NAPPING

Panelists and community members discussed their experiences when waking up from a nap.

- **Do you wake up feeling like yourself?  
Feeling refreshed?**

With narcolepsy, waking up may not always be a clear experience. Many people with narcolepsy report feeling **confused, groggy, grumpy, or even angry over little things.**

Dr. Ortiz described the varied experiences of children with narcolepsy waking up, as reported by their parents:

"It's a spectrum and I feel that represents different parts of the wake-sleep circuitry being kind of broken or malfunctioning."

- **How do you navigate when you wake up not feeling like yourself?**

In Julie's last relationship, they had a rule of not speaking until 30 minutes had passed after she woke up, in order to give her time to feel like herself.

If Mary notices she is not ready to be awake, she goes back to sleep.

Dr. Ortiz explained that sometimes he wakes up feeling good, but motivation doesn't kick in for another hour or two, when his brain "shifts gears" to get the day started.

“ Sometimes I don't wake up feeling very refreshed--everything seems really loud to me. If I'm waking up and not quite ready to be up, I get bothered by the slightest of sounds at all.

- Mary

“ While napping, I may look like Sleeping Beauty, but waking up I'm never quite sure who I'll be--a kind calm beauty or an angry beast.

- Julie

“ I find if I don't get up when I first wake up from a nap, I end up really groggy and grumpy.

- Richelle

“ My poor husband is like, 'Why are you so angry?' And I have no memory of why I felt that way.

- Lauren



"Let her sleep, for when she wakes, she will **move mountains.**"





# RESOURCES

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Here are some of our favorite resources. 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](#)

## OTHER RESOURCES

- [Doctors with Narcolepsy Video](#)

## RESEARCH

Garma L, Marchand F. Non-pharmacological approaches to the treatment of narcolepsy. *Sleep*. 1994 Dec;17(8 Suppl):S97-102. doi: 10.1093/sleep/17.suppl\_8.s97. PMID: 7701208.

Mullington J, Broughton R. Scheduled naps in the management of daytime sleepiness in narcolepsy-cataplexy. *Sleep*. 1993 Aug;16(5):444-56. doi: 10.1093/sleep/16.5.444. PMID: 8378686.

Reyner LA, Horne JA. Suppression of sleepiness in drivers: combination of caffeine with a short nap. *Psychophysiology*. 1997 Nov; 34(6):721-5.

Dinges DF, Orne MT, Whitehouse WG, Orne EC. Temporal placement of a nap for alertness: contributions of circadian phase and prior wakefulness. *Sleep*. 1987 Aug; 10(4):313-29.



# 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](http://www.project-sleep.com)

