narcolepsy

nerd alert

SLEEP PARALYSIS + HALLUCINATIONS TOOLKIT

Created by:

projectsleep

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TOOLKIT INDEX

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 coping with sleep paralysis and hypnagogic and hypnopompic hallucinations. 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. Project Sleep broadcasts each live event via Facebook, with host 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 and 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

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.

SLEEP PARALYSIS & HALLUCINATIONS

Sleep paralysis and hypnogogic and hypnopompic hallucinations are core symptoms of narcolepsy. These confusing and often scary experiences can happen while you're falling asleep (hypnagogic) or waking up (hypnopompic). Throughout history, some cultures have pointed to supernatural causes, and depictions can be found in art and literature. More recently, researchers have identified possible mechanisms in the brain. As of now, scientists are still learning how sleep paralysis happens, and why it happens more frequently for people with narcolepsy.

On December 8, 2022, Rising Voices advocates Chelsea Cataldi, Connor Baker, and Kristyn Beecher joined host Julie Flygare to share their experiences with sleep paralysis and hallucinations. In this toolkit, you'll find the latest scientific explanations, historical context, powerful example stories from people living with narcolepsy, and ideas for managing these difficult experiences.

- Watch the **Sleep Paralysis & Hallucinations** video or listen to the podcast: project-sleep.com/narcolepsy-nerd-alert-sleep-paralysis-hallucinations/
- Learn more about the **Narcolepsy Nerd Alert Series**: project-sleep.com/narcolepsy-nerd-alert/

Stumped on a term? See the glossary at the end of the toolkit.

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MEET OUR GUESTS

Chelsea Cataldi is a world traveler who enjoys creating things with her hands. She was diagnosed with narcolepsy with cataplexy in 2010. As a speaker with Project Sleep's Rising Voices program, Chelsea raises awareness to combat misperceptions about narcolepsy and let others know they're not alone.

Connor Baker is a nurse living in Aurora, Illinois. He was diagnosed with narcolepsy with cataplexy at 20 years old. Connor shares his story as a Rising Voices speaker to spread awareness and end stigma surrounding narcolepsy.

Kristyn Beecher is a storyteller and news producer in Houston, Texas. She was diagnosed with narcolepsy without cataplexy at age 24 after living with symptoms for many years. She's a graduate of Hampton University and a Rising Voices speaker. Kristyn works daily to make sure underrepresented voices are heard and their stories are shared.

MEET THE HOST

Julie Flygare, JD, serves as President & CEO of Project Sleep. She was diagnosed with narcolepsy with cataplexy at age 24 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.*

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SLEEP PARALYSIS

What is sleep paralysis?

Sleep paralysis is a phenomenon in which a person experiences a **temporary inability to move or speak** during the transition between sleep and wakefulness. It occurs when the body is in a state of paralysis that normally occurs during rapid eye movement or dream stage sleep, but persists after the person has awakened.

Some people may feel **restricted breathing** or **crushing weight on their chest**. Sleep paralysis is often, but not always, accompanied by **hypnagogic or hypnopompic hallucinations**.

> It felt like there was this darkness and weight on top of me. It was super hard to breathe and I couldn't scream. I couldn't do anything.
>
> - Chelsea

> When I have the feeling that someone's holding me down or trapping me, I wake up swinging. There was a time when it was nightly and it was so bad that my wife and I weren't sure if we could share a bedroom.
>
> - Connor

Important: People *without* narcolepsy can experience sleep paralysis, usually during periods of high stress or sleep deprivation. So just because someone has had sleep paralysis before does not necessarily mean they have narcolepsy. Studies suggest that between 8% and 30% of the general population will experience sleep paralysis at some point in their life. For people with narcolepsy, they tend to experience sleep paralysis more frequently and consistently over time.

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Why does sleep paralysis happen?

If you've experienced sleep paralysis, it can feel very frightening and confusing. Interestingly, it's the result of a **mistimed sleep mechanism**.

Humans have two distinct types of sleep: slow-wave deep sleep and rapid eye movement (REM) dream sleep. During REM/dream sleep, our brains become very active with our eyes darting from side-to-side and thoughts and emotions, believed to be the basis of our dreams.

> REM sleep is a remarkably active state... Certain parts of the brain are up to 30% more active during dream sleep relative to when we're awake. Regions of the brain that control our emotions, motor activity, and visual processing all light up during REM sleep.
>
> - Dr. Matthew Walker

As one's brain enters REM/dream sleep, it sends a signal to the body to paralyze all voluntary muscles (technically called "muscle atonia"). Meanwhile, important *involuntary* functions like breathing and heartbeat continue working, while *voluntary* muscles, in our neck and limbs, become paralyzed and unable to move.

It's believed that the body's voluntary muscles are paralyzed specifically during REM/dream sleep **so that we don't act out our dreams, as this would be quite dangerous**. From an evolutionary perspective, this likely kept our prehistoric ancestors from moving around at night, which would have made them vulnerable to hungry nighttime predators. Today, this paralysis still keeps us safe, as acting out dreams puts us and bed partners at risk of injury.

Generally, this muscle paralysis should **only** take place when we are unconscious and unaware of it during REM/dream sleep. However, during sleep paralysis, this paralysis occurs either **too quickly** (as we are still somewhat conscious and falling asleep) OR **continues too long** (as we are waking up and becoming aware of our body and surroundings). The mistimed paralysis leads to strange and frightening feelings of being awake but not being able to control or move one's own body.

How does the brain paralyze voluntary muscles during REM sleep?

While you're sleeping, your brain uses a combination of **electrical signals** and **neurotransmitters** to communicate with your muscles and sensory neurons. The paralysis of REM/dream sleep is a complex phenomenon that scientists are still working to better understand. Likely, many neurotransmitters and pathways contribute. See the Appendix for a deeper dive on this topic.

Why does sleep paralysis occur more frequently in individuals with narcolepsy?

People with type 1 narcolepsy with cataplexy have a deficiency in the neurotransmitter **orexin** (also known as hypocretin). Orexin plays many important neurological roles, including helping to **regulate features of REM/dream sleep** such as its muscle paralysis, and **stabilizing the boundaries between sleep/wake states**. This may explain why the loss of orexin neurotransmitters may lead people with type 1 narcolepsy's brains to more frequently **mistime** REM/dream sleep's paralysis, leading to sleep paralysis more consistently over time. People with type 2 narcolepsy without cataplexy may also experience frequent sleep paralysis, yet more research is needed to better understand why.

What if someone acts out their dreams at night?

It's important to know: REM Sleep Behavior Disorder (RBD) is a condition that causes people to act or talk out their dreams ("dream enactment") during their REM/dream sleep. Dream enactments can be very active, leading to potential injuries from falling or striking an object or bed partner. There are several risk factors for RBD, including being above age 50, having narcolepsy, environmental exposures, taking certain antidepressants, or severe head injury. People with RBD often, but not always, develop a neurodegenerative condition later in life such as Parkinson's Disease or Lewy Body Dementia. RBD will affect 5% of the population over age 60, sometimes subtle and going unnoticed for years, especially without a bed partner.

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HYPNAGOGIC & HYPNOPOMPIC HALLUCINATIONS

Hypnagogic (when falling asleep) and hypnopompic (when waking up) hallucinations are vivid, powerful experiences that take place around sleep, at night, and around naps. They can be visual (seeing things), auditory (hearing sounds), tactile (feeling touch), or involve other senses.

What distinguishes these from more typical dreams or nightmares?

Hypnagogic and hypnopompic hallucinations generally differ from average "nightmares" and "dreams" in that these hallucinations often take place in the actual space where the individual is sleeping (e.g. believing you are waking up in your bed but seeing an intruder open the bedroom door). More general nightmares and dreams often occur in **other places or dreamscapes** (e.g. dreaming you are at the mall with friends, in someone else's house, or running in the woods); generally these are not confused with reality.

Common themes of hypnagogic and hypnopompic hallucinations include but are not limited to:

- **an intruder** - someone breaking into home or attacking person in bed
- **an incubus** - in folklore, a demon or evil spirit that lies on a sleeping person, including one that has intercourse with people while sleeping
- **a shadow figure** standing in a corner or sitting in a chair
- **a roommate or loved one** who could logically be walking by or entering the bedroom
- **unusual body experiences** (e.g. floating or detached limbs)
- **music, name being called, random sounds** (e.g. knocking on the door or window, clapping, static radio, people talking in the next room)
- **animals or insects** - spiders, snakes, or domestic animals like a cat scratching
- **zaps, electric current, vibrating, buzzing**

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Hypnagogic and hypnopompic hallucinations can be confusing and hard to recognize as not "real" initially. First-hand accounts are so powerful:

> My first hallucination was a man coming into my bedroom. I remember him reaching out toward my neck. I was terrified thinking he was about to strangle me.
>
> - Julie

> I've had auditory hallucinations while feeling awake. I was hearing club music in my head, people chattering, the DJ talking. The music was so loud I felt like it was pumping out of my ears.
>
> - Sakhara

> I didn't think I was dreaming. I thought I was being haunted by spirits or something.
>
> - Chelsea

> I was 100% certain that I was awake when these things were happening. I wouldn't say I'm superstitious, but I thought some supernatural stuff was going on.
>
> - Connor

> I had a hallucination that there was an intruder coming in and taking my son from his bed. I also had paralysis at the same time. It was the single most scary event of my life—and it wasn't even real.
>
> - Rhi

> I don't think I've ever had a hallucination that wasn't scary.
>
> - Iris

> It's so scary. I have to ask family if what I experienced actually happened.
>
> - Chelsea D.

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HISTORY

Sleep paralysis and hypnagogic/hypnopompic hallucinations have been described for at least 2000 years across many cultures.

In the centuries preceding our medical understanding of the phenomena, these experiences were interpreted in a number of culturally-specific contexts. Even the word *nightmare* is derived from the old English word *maere:* a hostile figure who lies upon and immobilizes or suffocates sleepers.

Depiction from Romanian folklore

Some of the most common spooky visitors believed to cause sleep paralysis in history and folklore include:

- **Witches:** Legends originate from all over the world involving a witch or "hag" who sits on a sleeper's chest, inducing terrifying dreams and inability to breathe.
- **Ghosts:** In many Asian countries, sleep paralysis has been attributed to ghosts lying down on sleeping victims.
- **Demons:** In Middle Eastern and African countries, sleep paralysis has often been attributed to demons crouching on the chests of sleepers in order to suffocate, hurt, or possess them.
- **Vampires:** Accounts of undead individuals immobilizing and muting sleeping victims to drink their blood spread panic across Southeastern Europe in the 18th century.
- **Aliens:** A frequent feature of North American alien abduction narratives is the feeling of being completely paralyzed and trying to scream for help but being unable to make a sound—standard sleep paralysis.


Henry Fuseli: *The Nightmare*, 1783

Jean Pierre Simon: *Cochemare*, 1810

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POPULAR MEDIA

While these recent cultural examples might not be direct depictions of sleep paralysis and hypnagogic/hypnopompic hallucinations, they do have very strong parallels!

Stranger Things:

In the screenshot on the right, Vecna immobilizes Max while he attacks her in an altered dimension. Similar occurrences happen throughout season 4 of the series, and the "Upside Down" is a shadowy, corrupted version of reality similar to how surroundings may appear in hallucinations.

https://youtu.be/DJDPy5F-DEg

Harry Potter:

In the screenshot on the right, a dementor is attacking Harry and sucking out his soul. Harry is frozen and can't breathe.

https://youtu.be/UQR3yI-dCXQ?t=45

"Bury a Friend" by Billie Eilish:

The song and music video "Bury a Friend" strongly suggest sleep paralysis & hallucination experiences.

Eilish has disclosed having Tourette Syndrome (TS), and disrupted sleep is associated with TS.

https://youtu.be/HUHC9tYz8ik

The Haunting of Hill House:

In episode 5 of the series, Nell sees the Bent Neck Lady while frozen in her bed, unable to speak or move but feeling wide awake.

In this episode, Nell actually speaks with a medical professional who identifies the experience as sleep paralysis.

https://youtu.be/X7WgMbFsreU

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COPING STRATEGIES

There are currently no FDA-approved treatments specifically for sleep paralysis or hallucinations, however some treatment options (such as nighttime medications) can reduce their occurrence. Coping strategies vary person-to-person; here are some suggestions from our guests and audience members:

- **Managing fear and anxiety.** Being trapped in a state of paralysis can be terrifying, especially if hallucinations are occurring at the same time. Finding a way to recognize that what's happening isn't real may help you stay calmer and possibly help episodes end sooner.

> "I remind myself that the scary thing isn't real, and even if it was real, I can't do anything about it. So I tell myself to accept it rather than fighting it. That allows me to go completely to sleep.
>
> - Julie S.

> "I've realized that if I'm questioning whether I'm awake or not, that means what I'm seeing is probably not happening, because I never question if I'm awake when I actually am.
>
> - Julie

- **Noticing environmental triggers.** Some people notice that hallucinations often appear where there are shadows or specific shapes in their bedroom. Closing closet doors or replacing/rearranging objects in your room may be one way to limit this.

- **Maintaining a sleep routine** can make a difference. Connor says, "Basic sleep hygiene tends to help somewhat, but it's not a guarantee that this won't happen."

> "It doesn't happen as much if I sleep on my side or stomach.
>
> - Michelle

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- **Paying attention to patterns** might help you emotionally prepare for paralysis episodes. Kristyn says, "If I've been having problems for a few nights in a row, I'm like 'I need to do something different.' Maybe get more sleep, not look at my phone before bed, or try to see what is emotionally triggering me."

> After traveling or a major schedule change, I'll usually have a few paralysis episodes. But now I feel less anxious about it because it's not a surprise.
>
> - Taylor

- **Pets' behavior** is grounding for many people and makes it easier to recognize the hallucinatory nature of a scary experience. Connor says, "While I was coming out of an episode, my wife asked, 'What can I do? Do you want me to get one of the dogs?' and I said 'Yeah, get Bella. I know Bella would protect me if something is actually there.' Having my dogs near also helps get me out of 'the loop.' It's a cycle where I'll come back to for moments, and then I'll fall back into paralysis and hallucinations. And it just happens over and over again, sometimes for hours. But for some reason, whenever we get my dog in the bed with us, she kind of grounds me to reality."

- **Trying not to fight exhaustion or the urge to sleep.** Connor says, "If I fight sleep, it's almost a guarantee that I'm going to have an episode."

- **Addressing fears and phobias.** Desensitizing yourself to things that scare you even while you're fully awake may help prevent them showing up as hallucinations. Limiting your exposure to frightening content may help too. For example, Julie avoids scary movies. She says, "I don't need any more material for my hallucinations."

> I used to hallucinate about large snakes. Then I started to learn more about snakes, and I no longer have them in my bed.
>
> - Chelsea D.

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ART

For some people who experience sleep paralysis and hallucinations, art can be a helpful way to process.

A therapist once encouraged Chelsea to paint a scary figure from a hallucination. Chelsea says, "I left the painting up in my bedroom for a while, and she's not scary to me anymore."

Creating art from her hallucinations gives Chelsea feeling of **ownership & control** over the frightening experiences.

Chelsea described a frightening hallucination of a woman with no face (seen in the dark square). Chelsea chose to create a face for the woman (seen in the larger painting) to make the hallucination feel less scary.

Chelsea painted this beautiful, pale lady with a cloak and gnashing metal teeth.

> By using my hallucinations in a creative way, I take ownership of them and I can manipulate them.
>
> - Chelsea

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POETRY

Poetry is another creative way to express experiences with sleep paralysis and hallucinations. Elizabeth Wilson shared her poem "Night Fall" with us.

Elizabeth was diagnosed with type one narcolepsy with cataplexy when she was 38 years old. She is a graduate of Project Sleep's Rising Voices program and an award-winning poet. In 2022 Elizabeth published her first book of poetry, *Windowpanes*.

ELIZABETH WILSON

Night Fall

I'm electric. A current
ripples from my crown

to my toes. The ossicles
in my ears hum and whir.

I'm restrained by a witch
stronger than gravity—

Her incantations press
against my chest, crush

my breath. *This is a dream*,
I tell myself, a nightmare

for the waking. If I can just
move my pinky finger

I'll break her spell: I'll wake up.
Night will fall around me.

SUPPORT

Social support and accommodations are critical for dealing with narcolepsy symptoms, including sleep paralysis & hallucinations.

- **Give flexibility around timing of naps**. Julie says if she had an episode during a nap, she may want more time to adjust to reality before talking to others.
- Chelsea says that when she was living alone, it was helpful to **talk to a family member on the phone** after coming out of an episode. She says, "If I was able to actually speak with someone, it would make me awake and more alert. I would call my mom and just talk to her for a few minutes. We would usually talk about something that had nothing to do with the hallucinations, like some calming topic or mundane daily discussion."
- Connor works the night shift at a hospital, so he emphasized that his **co-workers have to be aware of his condition and allow for breaks right away**. He says, "I let them know what's going on, and get accommodations, so that whenever I say I need to take my break, it's not really a *'let's put it off for an hour'* kind of thing—it's a, *'hey, I gotta go'* type of situation."

> Don't be afraid to share with whoever you need to get what you need. Advocate for yourself… If you can get people to understand, they will generally be there for you.
>
> - Connor

Frequent sleep paralysis & hallucinations can be stressful for the person experiencing the episodes **and for loved ones**. As a caring supporter, it may be hard to hear that there's no way to fix this or to stop it from occurring. However, being aware of the symptom, trying to understand the cause, and looking for ways to be supportive are incredibly meaningful.

For more ways to support loved ones, check out our Friends + Family + Narcolepsy toolkit: project-sleep.com/narcolepsy-nerd-alert-friends-and-family/

RESOURCES

Here are some of our favorite resources. We look forward to hearing what our fellow #NarcolepsyNerds find helpful for understanding and managing sleep paralysis & hallucinations.

RECOMMENDED READING

- ***The Terror That Comes In the Night*** by David J. Hufford
- **"Spooky Nighttime Visitors: Paranormal or Parasomnia?"** https://project-sleep.com/spooky-nighttime-visitors-paranormal-or-parasomnia/

POPULAR MEDIA:

- Excerpt from ***Stranger Things*** (Season 4, Episode 1): https://youtu.be/DJDPy5F-DEg
- Excerpt from ***Harry Potter and the Order of the Phoenix***: https://youtu.be/UQR3yI-dCXQ?t=45
- "**Bury a Friend**" by Billie Eilish: https://youtu.be/HUHC9tYz8ik
- **Billie Eilish Shares Her Experience With Tourette's**: https://www.billboard.com/music/pop/billie-eilish-tourette-syndrome-david-letterman-interview-1235074298/
- Excerpt from ***Haunting of Hill House*** (Season 1, Episode 5): https://youtu.be/X7WgMbFsreU

PATIENT ORGANIZATIONS

- Major US Organizations:
  - Hypersomnia Foundation: https://www.hypersomniafoundation.org/
  - Narcolepsy Network: https://narcolepsynetwork.org/
  - Project Sleep: https://project-sleep.com/
  - Wake Up Narcolepsy: https://www.wakeupnarcolepsy.org/
- International Organizations:
  - Listed on Project Sleep's World Narcolepsy Day webpage: https://project-sleep.com/worldnarcolepsyday/

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GLOSSARY

Disrupted nighttime sleep: A feature of narcolepsy which includes increased awakenings, arousals, sleep stage transitions, and light sleep. This might feel like drifting in and out of sleep all night.

Glycine: A type of neurotransmitter with many functions in the nervous system, primarily inhibiting or blocking other processes.

Hallucinatory phenomena: Visual, auditory, or tactile hallucinations upon falling asleep or waking up. These can be frightening and confusing. See hypnagogic hallucination and hypnopompic hallucination.

Hypnagogic hallucination: Visual, auditory, or tactile hallucinations upon falling asleep.

Hypnopompic hallucination: Visual, auditory, or tactile hallucinations upon waking up.

Hypocretin: A type of neurotransmitter involved in the regulation of sleep and wakefulness. Also called orexin.

Incubus: In folklore, an evil spirit that lies on a sleeping person, including one that has intercourse with people while they are sleeping.

Medulla: Part of the brainstem that joins the spinal cord to the rest of the brain. It also controls heartbeat, breathing, and blood pressure.

Neurons: The cells that make up the brain and nervous system. Also called nerve cells or brain cells.

Neurotransmitters: Proteins used by the nervous system to transmit messages between cells. Also called chemical messengers or hormones.

Noradrenaline: A type of neurotransmitter involved in the regulation of arousal, attention, cognitive function, and stress reactions.

Non-rapid eye movement (NREM) sleep: A state of dreamless sleep, characterized by a specific type of brain activity called delta waves. NREM is divided into stages which range from light to deep sleep.

Orexin: A type of neurotransmitter involved in the regulation of sleep and wakefulness. Also called hypocretin.

Orexin neurons: A group of cells in the brain which produce and release the neurotransmitter orexin. Also called orexin-producing neurons, orexin/hypocretin neurons.

Pons: Part of the brainstem that handles unconscious processes and jobs, such as the sleep-wake cycle and breathing. It also contains several junction points for nerves that control muscles and carry information from senses.

Rapid eye movement (REM) sleep: A stage of sleep associated with dreaming and memory consolidation.

REM muscle atonia: Paralysis, or suppressed muscle activity, during the REM sleep phase.

REM-off brain cells: Cells which perform specific functions when the brain is not in the REM sleep phase.

REM-on brain cells: Cells which perform specific functions when the brain is in the REM sleep phase.

Serotonin: A type of neurotransmitter which carries messages between the brain and the rest of the body.

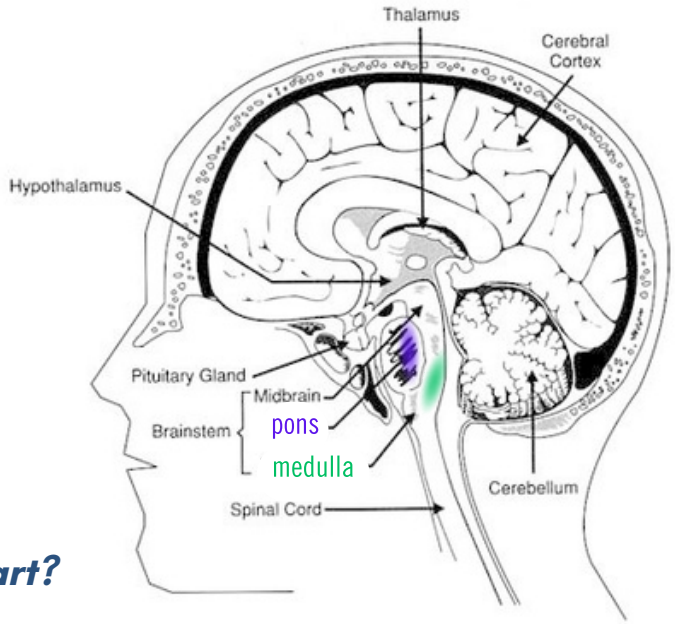
Sleep paralysis: A temporary inability to move or speak while falling asleep or upon waking. Episodes are usually brief — lasting a few seconds or minutes — but can be frightening and are often accompanied by hypnagogic or hypnopompic hallucinations.

Tourette syndrome (TS): A neurological disorder that involves repetitive movements or unwanted sounds (tics) that can't be easily controlled.

APPENDIX

Where in the brain does sleep paralysis occur?

Specific regions of the brain play distinct roles in regulating sleep and wake states. Muscle atonia is thought to be controlled by a small center in the **pons** and by part of the **medulla** which connect to the spinal cord as shown in the diagram on the right.



How does muscle atonia start?

There's a cluster of cells found in the medulla, a region near the brainstem, which are active during REM sleep. When these cells are active, they release chemical messenger proteins GABA and glycine.

At the same time, another part of the dreaming brain creates electrical impulses which would signal movement when they travel down the spinal cord to the voluntary muscles found throughout the body.

The GABA and glycine proteins travel to the spinal cord where they attach to motoneurons and block electrical signals from the brain. This means that the motoneurons do not relay the brain's message to the muscles, and therefore you don't act out the dream.

It can also start in the pons when REM-on cells release glutamate. This indirectly triggers paralysis, as glutamate activates the previously mentioned GABA and glycine neurons.

If the REM-on cells start releasing GABA and glycine before sleep onset, the brains signals for voluntary movement are also blocked at the spinal cord, which means that no matter how hard you think about it, you can't raise your arm.

How does muscle atonia end?

Hypocretin-producing cells give the signal to reverse REM atonia. When other brain cells receive the signal, they release serotonin and noradrenaline to "reactivate" the motoneurons. Again, this is one part of a complex mechanism, but it helps explain why people with narcolepsy experience sleep paralysis so frequently and consistently.

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, sleep equity, and sleep disorders.

More resources at: www.project-sleep.com

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