

SLEEP DISORDERS:
A TOOLKIT
FOR JOURNALISTS

Created by:

project[★]sleep

TOOLKIT INDEX

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AN EPIDEMIC OF EXHAUSTION

From ergonomic pillows to melatonin gummies, Americans are spending \$65B annually in pursuit of a good night's sleep. Unfortunately, for those living with a chronic sleep condition, it doesn't matter how good your mattress is; there will still be unresolved issues, and serious, even life-threatening health complications are real possibilities.



Sleep disorders affect one in five Americans, yet the majority remain undiagnosed and without access to treatments and support.

projectsleep

Project Sleep is a 501(c)(3) non-profit with a vision to make sleep cool! As a national leader in sleep advocacy and awareness, Project Sleep recognizes that the media is one of our greatest allies in the effort to educate people about sleep disorders. For this reason, we strive to work with the media to tell stories that accurately reflect real-life experiences that will resonate with the public. Project Sleep can provide background information for stories and sources of people living with sleep disorders, researchers, and medical professionals.

WHAT ARE SLEEP DISORDERS?

According to the CDC, an estimated 50 - 70 million Americans chronically live with sleep or circadian-related conditions. Sleep disorders are real and need to be addressed by a sleep specialist.¹

Sleep and circadian-related disorders are often invisible and may be hard to detect. Sleepiness may manifest as issues with behavior, mood regulation, memory, concentration, or sustained attention.

TYPES OF SLEEP DISORDERS

Hypersomnias

- Narcolepsy
- Idiopathic Hypersomnia
- Kleine-Levin Syndrome

Circadian Rhythm Disorders

- Delayed Sleep Phase Disorder
- Non-24 Sleep-Wake Disorder
- Advanced Sleep Phase Disorder
- Irregular Sleep Wake Disorder
- Shift Work Disorder

Movement Disorders

- Restless Legs Syndrome
- Periodic Limb Movements

Breathing Disorders

- Obstructive Sleep Apnea
- Central Sleep Apnea

Parasomnias

- REM Sleep Behavior Disorder
- Sleepwalking
- Night Terrors
- Sleep Paralysis
- Sleep Hallucinations

Insomnia

Sleepiness and sleep disorders are serious health concerns and cannot always be mitigated by healthy sleep habits. Untreated sleep disorders are linked to an increased risk for accidents, anxiety, memory issues, obesity, high blood pressure, heart disease, diabetes, depression, and strokes.



SLEEP DISORDERS IMPACT MANY CHILDREN

One recent study indicated that undiagnosed sleep disorders are linked to higher suicide rates in adolescents. The researchers found that adolescents with undiagnosed sleep disorders exhibited over a **threefold increase** in the likelihood of experiencing **suicidal ideation** compared to their peers without such disorders.²

WHY ARE SLEEP DISORDERS SO HARD TO DIAGNOSE?

Medical professionals are receiving less than two hours of education on sleep health and disorders.³ This often leads to people with sleep disorders being misdiagnosed or have their concerns dismissed as stress, adolescent growth, hormonal issues, or part of the normal aging process.

With a lack of public understanding around sleep disorders or misrepresentations (ie. person with narcolepsy falling asleep in their food) people do not have the language to express their full concerns to their medical professionals.

Additionally, due to current and historical injustices that have given rise to social, economic, and environmental inequalities, people from BIPOC, LGBTQ+, disabled, and other minoritized communities are more likely to get insufficient, poor quality sleep, are more likely to have sleep disorders, less likely to receive screening for sleep health issues, and more likely to be undiagnosed and untreated for sleep disorders.

Sleep conditions often go undetected for years or decades and should be addressed by **a Board-Certified Sleep Specialist.**



HOW JOURNALISTS CAN HELP



Recently, we've seen a shift away from the storyline that we don't need sleep toward encouraging people to get a full night's rest. However, even with this positive trend, nearly 70 percent of adults report insufficient sleep or rest at least once a month, and 11 percent report insufficient sleep daily.

Millions with undiagnosed sleep conditions are facing these conditions alone, thinking their challenges are something they should be able to control, a sign of laziness, or a character flaw. Unfortunately, reading sleep health tips alone without mention of sleep disorders leaves these individuals feeling like they are failing, without the next steps for diagnosis or treatment. Journalists can seamlessly integrate content about sleep disorders into stories they're already writing. This toolkit not only highlights the importance of covering sleep disorders but also provides guidance on how to effectively write about them and direct audiences toward valuable next steps like Project Sleep's Sleep Helpline™, the Sleep Disorders Screener, and board-certified sleep specialists.

Journalists are among our most important allies in the effort to reduce stigma and raise accurate awareness about sleep disorders. Media and communications professionals are well-positioned to share stories and create sleep-related content that resonates with audiences, conveys accurate and insightful information, and empowers individuals to take action and seek medical care.

Through greater access to information and real-life stories more people can recognize their own experiences and reach an accurate sleep disorder diagnosis sooner.

STIGMA, STEREOTYPES & SLEEP DISORDERS

Due to lack of awareness and inaccurate Hollywood portrayals of sleep disorders, most Americans (including doctors) are not familiar with basic signs and symptoms of the most common and serious sleep conditions. This lack of awareness directly contributes to misdiagnoses and delays in accurate diagnosis lasting years or even decades, leaving people with sleep disorders without access to care and effective treatment.

Beyond delays to diagnosis, lack of information and inaccurate portrayals of sleep disorders leads to stigma associated with people with sleep disorders that can hamper employment or educational opportunities.

COMMON MISPERCEPTIONS OF SLEEP DISORDERS:

- People with narcolepsy are often labeled by teachers, co-workers, supervisors, and others as antisocial, lazy, or faking. They report feeling socially isolated, inferior to others, and hesitant to disclose their disorder (Broughton and Broughton 1994, Kapella et al. 2015).⁴
- A common stereotype of obstructive sleep apnea is that it only impacts older, overweight men (Young et al. 2004).⁵
- Insomnia is perceived as trivial or purely psychiatric/behavioral (Stinson et al. 2006, Henry et al. 2013).⁶
- Restless leg syndrome is misunderstood only to affect older adults and is often referenced as a joke, not a serious neurological disorder. Reports in the news continue to promote the fallacy that placing a bar of soap under your sheets at night will “cure” RLS.⁷

WHY INCLUDE SLEEP DISORDERS WHEN COVERING SLEEP?

Responsible coverage of sleep health must include sleep disorders.

People with undiagnosed sleep disorders do not know that they have a sleep disorder, and will turn to general sleep articles to cope, not realizing that their issues go beyond self-help tips and should be addressed by a sleep specialist.

Talking about sleep habits and ways to enhance your sleep is important. But equally important is sharing that if you are prioritizing your sleep and still have trouble sleeping at night or functioning during the day, you may need medical attention.



In addition to including sleep disorders in discussions of sleep health, it's important to share first-hand descriptions of what symptoms look and feel like. Distorted movie and TV portrayals, medical jargon, and abstract definitions often obscure lived experiences, so hearing real-life examples provokes "aha" moments of recognition in people living with undiagnosed sleep disorders, encouraging further exploration with a healthcare provider.

HOW LANGUAGE CAN LEAD TO MISDIAGNOSIS:

- People with undiagnosed **obstructive sleep apnea** often have bed partners who complain about their snoring. Snoring is so common that society sees it as an annoying but harmless trait to make jokes about, not a potential sleep disorder symptom.

- Individuals with **restless legs syndrome (RLS)** often describe a compelling urge to move with accompanying sensations (creepy, crawly, tingly) that worsen in the evening and/or night and are relieved by movement; these complaints are often dismissed as psychological.

- One of the symptoms of **narcolepsy** (a neurological disorder of the sleep-wake cycle) is sleep paralysis, a temporary inability to move or speak while falling asleep or waking up. Sleep paralysis is often accompanied by hypnagogic or hypnopompic hallucinations, which are visual, tactile, and/or auditory hallucinations that can be terrifying and confusing. People with undiagnosed narcolepsy often interpret this as vivid nightmares, which can easily be dismissed by medical professionals as stress.

This makes telling the stories of people with sleep disorders incredibly important so people can see themselves in the experiences of others.

LANGUAGE TO USE

Project Sleep recommends using people-first language and a balanced, neutral perspective that respects individuals' autonomy.

PUTTING PEOPLE FIRST:

People-first terminology literally puts the word "people" or "person" before the name of their condition. Using people-first terms signals that a diagnosis is something a person has, not a person's defining characteristic.

Using people-first language is based on a scientifically-established phenomenon in which condition-first language subconsciously propagates stigma and dehumanization in the audience's mind. Since many people with sleep disorders often face stigma, this is important to ensure that media content does not unintentionally perpetuate stereotypes or negative attitudes about these conditions.

Journalists may worry that adopting people-first language will hinder their ability to use elegant shorthand, especially with limited space in headlines. However, convenience should not take priority over reducing stigma for the very people this coverage intends to help.

REFERRING TO PEOPLE WITH SLEEP DISORDERS:

| YES | NO | NEVER |
|---|---|---|
| [People, adults, children, etc.] with narcolepsy, living with idiopathic hypersomnia, diagnosed with sleep apnea | narcolepsy patients restless legs syndrome sufferers suffering from insomnia afflicted by Klien Levin syndrome | narcoleptic, narcoleptics, insomniac, insomniacs |

USING PRECISE AND NEUTRAL TERMS:

Cliches like “suffering from,” “afflicted with,” and “victim of” have strong emotional overtones and raise negative connotations. Suffering is a self-descriptive concept that one should not assume applies to another person or whole group of people. Describing what people “have” or “experience” is more precise and avoids imposing superfluous meaning. “Burden” is a value-laden word when discussing the effects of a sleep disorder on healthcare costs or on families. “Impact” or “costs” are more neutral terms to use in these contexts (e.g., “the economic impact of sleep apnea” rather than “the economic burden of sleep apnea”).

There is growing consensus that referring to treatment “adherence” rather than “compliance” better reflects a culture of shared decision-making in medicine. Lastly, in referring to people who participate in clinical trials and research studies, using the term “participant” rather than “subject” expresses greater respect for individuals who bravely step forward to take part in scientific research.

AVOIDING ABSOLUTES, GENERALIZATIONS AND EXTREMES:

Speaking in absolutes—using terms like “everyone,” “no one,” “always,” or “never” — can decrease credibility because absolutes leave no room for outliers and exceptions. No one person can represent everyone with a certain condition, yet audiences may not realize that people with sleep disorders have a variety of different experiences. As a journalist, you can help remind your audience that experiences vary from person-to-person.

Likewise, sensationalistic coverage (e.g., the most **extreme** places someone has fallen asleep) aiming to shock audiences into paying attention may make sleep disorders seem so “other worldly” or “out there” that people with undiagnosed conditions may not recognize themselves in the story. Try to include average everyday examples, not just the most extreme stories, to show the sneaky and often invisible ways that sleep disorders manifest in daily life.

AVOID SUPERFLUOUS & CHARGED LANGUAGE:

Avoid terms with overtones of excessive negativity, value judgment, or disempowerment.

| INSTEAD OF THIS: | USE THIS: |
|-------------------------------------|--|
| suffer, afflicted, victim, stricken | with, living with, diagnosed with |
| debilitating, disabling | serious |
| burden | costs, impact |
| compliance | adherence, completion |
| subjects | participants |

IMAGES TO USE

A picture is worth a thousand words. The images and videos chosen to support a story will set the tone and leave a lasting impression. Photos and videos can help someone “see” themselves in a story and dispel myths. Including people of all ages and members of minoritized communities is especially impactful, because sleep disorders do not only impact elderly white people. Images can also give hope that medical treatments and community support are available.

Consider images that provide honest depictions, without creating triggers or stigma.

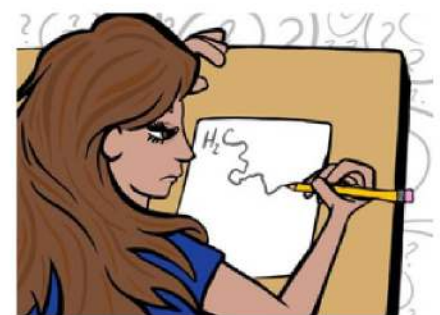
PRE-DIAGNOSIS SYMPTOM EXPERIENCE:

- Dark, blurred images, or head in clouds, to convey brain fog and invisible cognitive impacts during the day
- Surrealist nightscapes or dreamscapes to convey blurred boundaries between waking, sleeping and dreaming
- Close-up of eyes partially open or one eye closed to convey blurred boundaries between waking and sleeping
- Images of people from various age groups, backgrounds, genders and body types, including young women and children. (Let’s bust myths that sleep apnea only impacts older, overweight, white men! Let’s correct the misperception that RLS only impacts elderly people!)
- A person standing alone or looking out a window to convey feeling confused or isolated on their path toward diagnosis
- Depicting RLS with images of people pacing the floor at night, rubbing or massaging of legs

DIAGNOSIS, TREATMENT AND EMPOWERMENT:

- A person seeking help by filling out a sleep questionnaire, visiting a sleep center or talking with a sleep doctor to show someone taking action
- FDA-approved treatments and people using or holding treatments to convey that treatments are available
- Real individuals living with sleep disorders (with permission), possibly wearing awareness gear, holding awareness materials or actively advocating with policymakers

EXAMPLES OF APPROPRIATE IMAGERY:



IMAGERY TO AVOID:

- A person asleep over keyboard
- A person asleep while standing (Help dispel myths that narcolepsy is like the movies Deuce Bigalow: Male Gigolo and Rat Race.)
- A person asleep in an awkward position or embarrassing situation surrounded by people, being pointed at or laughed at (Let's debunk the assumption that sleepiness is a joke!)
- A person asleep in cereal or soup bowl
- Only including images of older, overweight, white men
- Children in school bouncing their leg uncontrollably under desk (not RLS)
- Adults shaking their legs when seated (not RLS)



CONSIDER THE STORYLINE



When considering stories about sleep disorders, the stories you choose matter. Some ideas to consider as you plan coverage about sleep and sleep disorders:

- Sleep disorders are real and cannot be mitigated by healthy sleep habits.
- Sleepiness is often hard to see, often manifesting as issues with behavior, mood regulation, memory, concentration, or sustained attention.
- Sleep disorders often disrupt people’s abilities to get quality sleep at night, furthermore impacting their ability to function during the day.
- If you think you or a loved one could have a sleep disorder, it’s important to consult a board-certified sleep specialist.
- The majority of people living with sleep disorders are undiagnosed and unaware of available treatment options.
- Treatments are available for many sleep disorders and can improve or resolve symptoms allowing people to regain their quality of life.
- You are not alone living with a sleep disorder. Community, education, and support are available through organizations like Project Sleep.
- Not all sleep issues are within personal control. Systems-level factors such as school start times, shift work, health care, housing, safety, living wages, and other social and economic barriers create sleep inequities that impact many people’s abilities to access a good night’s sleep, and disproportionately affect people in minoritized communities.

REAL SLEEP DISORDER STORIES

Project Sleep can connect journalists with these individuals along with additional people living with sleep disorders across the U.S. and around the world.



Emma Cooksey

Diagnosis: Obstructive Sleep Apnea

Age at diagnosis: 30 years old

Delay to diagnosis: 10 years

Hometown: St. Augustine, FL

Speaker, mom, host of "Sleep Apnea Stories" Podcast

*After constant exhaustion, multiple doctors told me it was unlikely I had sleep apnea, despite loud snoring and morning headaches, because I was a young, thin woman. When I was 30, I was driving home one day with my baby daughter strapped into her car seat. We were on a busy bridge when I felt **a deep sleepiness descend**. I blew cold air on my face to try to stay awake and focused my attention on the license plate of the big truck in front of me. In a split second that license plate was coming straight towards me. Realizing I had fallen asleep, I slammed on the brakes to avoid a collision.*

*Shaken by the experience, I pushed for a sleep study and finally got my diagnosis of **obstructive sleep apnea**. Women who are dealing with consistent drowsy driving should know that sleep apnea could be the underlying cause.*



Farah Hasan

Diagnosis: Idiopathic Hypersomnia

Age at diagnosis: 21 years old

Delay to diagnosis: 16 years

Hometown: Mississauga, ON, Canada

Graduate Student, Virtual Reality & Education Researcher

*In university, no matter how interested I was in the course content, it was nearly impossible to keep my eyes open during lectures. My notes were illegible. As I was trailing off, I would continue to take notes, leaving undecipherable glyphs on the page. Sometimes I would fall asleep two or three times in the span of writing a single word. If people asked for my lecture notes, I was happy to share, but with the caveat that if they could figure out what my notes said, I would love for them to share their translation! **I thought with enough scheduling, strategizing, and will power - I could regain control.***



Charles Phelps

Diagnosis: Restless Legs Syndrome (RLS)

Age at diagnosis: 75 years old

Delay to diagnosis: 4 years

Hometown: Rochester, NY

Health economist, woodworker, archer, Granddad

There is a strong genetic component to **RLS**. Many members of my mother's family, the McCleerys, had it unknowingly. We called it, "McCleery Legs" - hah, hah, cousin Margie has McCleery legs now! Jon Stewart called it, "Jimmy Legs," to the great amusement of his studio audience. But it's not funny if you have it. **It disrupts sleep, causes significant depression, and is so disruptive that one in six life-partners of people with RLS consider separation.** Most people, including doctors, don't know what it is or that it has treatments that work. People are embarrassed to talk about it with their healthcare providers. But it's hard to find medical help if you google "McCleery Legs."

It's a progressive disease, coming on slowly, sometimes years before it gets really disruptive. I knew about it earlier because my identical twin brother was diagnosed with it about 10 years ago. Which gave me a head start on nailing down my own symptoms in four years, ahead of the national average of 10 years.



Lauren Thomas

Diagnosis: Narcolepsy

Age at diagnosis: 29 years old

Delay to diagnosis: 14 years

Hometown: New York, NY

Speaker, brand strategist, warrior

I was hospitalized for asthma and made sure to alert my care team that I also had **narcolepsy** and made sure it was documented in my chart. One night when I had been sleeping peacefully, a nurse tried to wake me up for a vitals check. I was able to hear her calling my name but **I was unable to respond due to a sleep paralysis episode, the temporary inability to move or speak that occurs when waking up or falling asleep.**

Instead of noting that my vitals were stable and that I am a person with narcolepsy, they proceeded to start sternum rubs, a painful exercise designed to provoke a response. They also searched my personal belongings for illicit drugs that could have attributed to my sleepy state. It was extremely traumatic, humiliating, and unnecessary and left me feeling unsafe and unheard in a place that was supposed to be providing me care. When you have a rare disease it is often the patients job to educate medical professionals outside of sleep medicine speciality to ensure they receive adequate care and even still because of the nature of the disease you can find yourself paralyzed and unable to advocate for yourself.



Diane Macedo

Diagnosis: Insomnia

Age at diagnosis: 36 years old

Delay to diagnosis: 7 years

Hometown: New York, NY

Journalist, author, mom

“
For years I had trouble sleeping but I just assumed that I was just a “bad sleeper” and also chalked it up to my odd news hours. But it got so bad that I couldn’t ignore it anymore. So I tried all the typical sleep tips, and it kept getting worse. I read a couple of books but they just made me feel like I was doomed. I finally went to my doctor and she blamed it entirely on my hours and encouraged me to take Ambien. The pills worked like magic for a while, but eventually I formed a tolerance to them, and my doctor’s only recommendation was to take more. That was the turning point for me. I got tested for sleep apnea that came back negative. **I decided to tackle this as a journalist, combing through studies, reading sleep textbooks and books written by sleep clinicians, and that’s where I found my answers.** Within roughly 3 weeks of trying CBT-I based and circadian based tactics I was getting a full night’s sleep even while working the overnight shift! I couldn’t believe it. The stuff that fixed me was so simple and so counter to everything else that I had read about and tried up until that point, and I thought, “why is nobody talking about this stuff?” So I decided to write the book that I wish had existed when I was struggling. That’s how The Sleep Fix was born. I want others to know there is no one way to sleep, **insomnia is not your fault**, and that there are practical, evidence-based tools to fix it.

”

Lindsay Scola, 40 years old

Diagnosis: Narcolepsy

Age at diagnosis: 35 years old

Delay to diagnosis: 19 years

Hometown: Los Angeles, CA

Speaker, writer, impact strategist, dog mom

“
One night I was awoken by the voice of a child whispering, “hold my hand.” Terrified, I pulled the covers over my head and tried to get back to sleep. The next day the voice stuck in my head. Was my house haunted? It was an old bungalow in a historic Los Angeles neighborhood, maybe? I went out to purchase sage, walking room to room inviting my child ghost to peacefully exit my space. When we think of hallucinations we think pink elephants floating around the room. **One of the key symptoms of narcolepsy is hallucinating when waking up or falling asleep.** Some people see things, but others of us hear things, or even feel things. And it turns out my hallucinations were far more often and far less dramatic than I thought – I am regularly awoken by something falling, or someone screaming, or construction outside my window. Sometimes I hear my partner speak to me or the dog bark just to wake up and find them sleeping peacefully.

”

RESOURCES & NEXT STEPS

Here are practical next steps to include in sleep-related stories. Given that many primary care clinicians are unfamiliar with sleep disorders, we suggest that individuals reach out to the Sleep Helpline™, complete the Sleep Disorders Screener, or seek guidance from a sleep specialist. Incorporating these resources into your narrative provides valuable support for audiences seeking help but unsure where to turn.

CONTACT THE SLEEP HELPLINE

The **Sleep Helpline™** is a free national helpline providing individualized support for individuals navigating sleep issues or sleep disorders. Whether uncertain about a potential sleep problem, diagnosed with a sleep disorder, or acting as a caregiver or healthcare provider, Resource Specialists offer trusted information and connections to certified sleep centers and support organizations.



Phone: +1 800-819-2043

Email: helpline@project-sleep.com

Online: project-sleep.com/helpline

TAKE THE ONLINE SLEEP DISORDERS SCREENER

The **Sleep Disorders Symptom Checklist-25 (SDSCL-25)** is an important self-assessment tool to help individuals identify signs and symptoms of 13 major sleep disorders. This is a decision support tool and not a substitute for professional medical advice, diagnosis, or treatment, but can be a helpful resource. The online survey takes 3-5 minutes to complete at: sleephealthscreen.com

 **TAKE THE SELF-ASSESSMENT**

CONSULT A BOARD-CERTIFIED SLEEP SPECIALIST

While most people's journey begin with a primary care provider, it's important to consult with a board-certified sleep specialist when considering a possible sleep disorder. The American Academy of Sleep Medicine (AASM) sets standards and promotes excellence in sleep medicine, health care, education, and research. The AASM recognizes accredited doctors and sleep centers. For more information: aasm.org

TOPICS WITH SLEEP DISORDER TIE-INS:



You may already be covering topics that naturally complement discussions about sleep disorders. Consider integrating sleep disorder content and resources into existing coverage on:

- Fatigue v. sleepiness
- 24/7 non-stop go-go-go culture
- Productivity versus wellness and self-care focus
- Workplace burnout
- Gig culture
- Shift work
- Ignored and overlooked women's health issues
- Mental health concerns
- Health equity and health disparities
- Invisible illnesses, hidden disabilities
- Stimulant shortage, insurance coverage for medications and access issues

SLEEP AND RELATED AWARENESS DAYS

Sleep is important every day, but here are some official days to highlight sleep and sleep disorders.

| | |
|--|---------------------|
| Festival of Sleep Day | January 3, 2024 |
| Rare Disease Day | February 29, 2024 |
| National Sleep Awareness Month | March, 2024 |
| National Sleep Awareness Week | March 10 - 16, 2024 |
| Suddenly Sleepy Saturday | March 9, 2024 |
| World Sleep Day | March 15, 2024 |
| Sleep Apnea Awareness Day | March 20, 2024 |
| Project Sleep's Sleep In | March 15-17, 2024 |
| World Health Day | April 07, 2024 |
| Biological Clock Day | April 28, 2024 |
| World Day for Safety and Health at Work | April 28, 2024 |
| Sleep Apnea Awareness Day (Australia) | May 5, 2024 |
| Insomnia Awareness Night | June 21, 2024 |
| Circadian Awareness Day | July 24, 2024 |
| World Narcolepsy Day | September 22, 2024 |
| Restless Legs Syndrome (RLS) Awareness Day | September 23, 2024 |
| World Mental Health Day | October 10, 2024 |
| Non 24 Awareness Day (Non-24-Hour Sleep-Wake Disorder) | November 24, 2024 |
| International Day of People with Disability | December 03, 2024 |

ABOUT PROJECT SLEEP

MISSION:

Project Sleep is a 501(c)(3) non-profit organization dedicated to raising awareness about sleep health, sleep equity, and sleep disorders.

VISION:

Believing in the value of sleep, Project Sleep aims to improve public health by educating individuals about the importance of sleep health, sleep equity, and sleep disorders. Project Sleep educates and empowers individuals using events, campaigns, and programs to bring people together and talk about sleep as a pillar of health.



ABOUT PROJECT SLEEP



Project Sleep can connect you with people living with various sleep disorders across the U.S. and around the world. Project Sleep's Rising Voices storytelling program trains people with sleep disorders to effectively raise awareness and break down stereotypes. Rising Voices advocates are trained with communications best-practices to share their story via **presentations, articles, and media engagements**. Project Sleep is proud to have over 150 Rising Voices trained advocates in 18 countries around the world.

PROJECT SLEEP'S EXPERT ADVISORY BOARD



Project Sleep's Expert Advisory Board includes clinicians, researchers, and patient advocates who are thought leaders and trailblazers in their respective fields. This board marks one of the first times patient advocates have been included on a non-profit organization's Expert Advisory Board in the sleep space. We strongly believe that including people with first-hand lived experiences will foster more fruitful discussions and lead to better outcomes.

ABOUT PROJECT SLEEP



The Sleep Helpline™ is a free national helpline providing personalized support and resources for people facing sleep issues and sleep disorders. Reach out to speak with a compassionate Resource Specialist who will listen and help provide accurate sleep disorder information, resources to navigate daily living and the healthcare landscape, and connections to certified sleep centers and support organizations. The Sleep Helpline is provided by Project Sleep, a non-profit organization dedicated to sleep health, sleep equity, and sleep disorders.

CONNECT WITH US:

Speak one-to-one with a Resource Specialist:



1-800-819-2043



helpline@project-sleep.com



project-sleep.com/helpline

CONTACT US

For more information, resources, and sources:

Project Sleep

info@project-sleep.com

www.project-sleep.com



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SLEEP APNEA

WHAT IS SLEEP APNEA?

Sleep apnea is a type of sleep disordered breathing that affects up to 25% of adults in the US.

People with sleep apnea repeatedly have issues with their breathing during sleep, 5–15 times per hour in mild cases or up to hundreds of times per night in severe cases. The loss of airflow lowers the blood oxygen, triggering the brain to wake up. People with sleep apnea might not notice, or they might wake up gasping

PEOPLE WITH SLEEP APNEA
MIGHT NOT BE AWARE
OF THEIR SYMPTOMS.

The difficulty breathing during sleep could be caused by the airway falling closed and blocking air from flowing (obstructive sleep apnea) or, less commonly, by the brain not sending the signal to breathe (central sleep apnea). Both types keep people from falling into the deep sleep that their body needs, and put a strain on their long term health.

WHAT ARE THE SYMPTOMS OF SLEEP APNEA?

Sleep apnea symptoms vary by person and may include:

- Loud snoring or gasping sounds while sleeping, maybe noticed by a roommate
- Silent pauses in breathing while sleeping, maybe noticed by a roommate
- Waking up with a dry mouth or headache
- Waking frequently during the night to go to the bathroom
- Insomnia or waking often during the night
- Difficulty staying awake during the day (excessive daytime sleepiness)
- Feeling tired or unrefreshed, even after sleeping
- Difficulty concentrating and remembering
- Grumpiness and irritability
- Lower sexual desire and difficulty maintaining an erection

HOW IS SLEEP APNEA DIAGNOSED?

A healthcare provider will ask questions about symptoms and sleep, ideally with the help of a partner or roommate, if available. Sleep apnea is assessed with a **sleep study**, which uses stick-on sensors to measure things such as breathing, heart rate, brain activity, and body movements while asleep. The study can be done during an overnight stay in a **sleep center/lab** (called polysomnography) or **at home**. Home testing collects less information but may be more convenient for straightforward cases. A healthcare professional can help decide which is best.

HOW IS SLEEP APNEA TREATED?

There are several treatments for sleep apnea, and people may try multiple options or a combination to find one that works for them.

- **CPAP** (continuous positive airway pressure) is the most common treatment for sleep apnea. It is a device that pumps air through a mask to help the throat stay open while sleeping. There are many different shapes and sizes of masks to fit different faces.
- For milder sleep apnea an **oral appliance** (also called a mandibular advancement device), similar to a mouth guard, helps keep the airway open by moving the jaw forward.
- **Positional therapy** is helpful for people who mostly have sleep apnea when they are lying on their back, for example devices that buzz when you roll on your back, or a wearable cushion that keeps them sleeping on their side.
- **Surgery** to widen the airway, usually involving the nose, tongue, palate, or jaw.
- **Hypoglossal nerve stimulation** involves a small device implanted in the chest wall that triggers muscles to keep the airway open and continue breathing (about the size of a pacemaker).
- **Medications** may be prescribed to help people stay awake if they are still having difficulty despite other treatments such as CPAP.
- Helpful **lifestyle changes** could include keeping healthy sleep habits, developing a regular movement practice, avoiding alcohol before bed, and quitting smoking.
- **Cognitive behavioral therapy** can help to keep healthy sleep habits and adapt to and stick with CPAP or other treatment options.
- **Social support**, through connecting with other people who have sleep apnea, can empower people to cope with sleep apnea and learn strategies to manage symptoms and treatments.

PEOPLE MAY TRY MULTIPLE SLEEP APNEA TREATMENT OPTIONS OR A COMBINATION TO FIND ONE THAT WORKS FOR THEM.

INSOMNIA

WHAT IS INSOMNIA?

While everyone has an occasional sleepless night, approximately 35% of US adults have regular difficulty falling asleep (sleep onset insomnia) or staying asleep (sleep maintenance insomnia).

For most people, insomnia is mild or short term (lasting up to 3 months), but about 10% of people experience chronic insomnia (lasting more than 3 months). Insomnia is more common in older people and women. Short-term insomnia can be caused by many factors, including other medical issues, mental health conditions, certain medications, sleep habits, the sleeping environment, stress, major life events, shift work or frequent travel. Over time, the sleep difficulty can become chronic, typically through a process called "conditioned arousal" where the stress of sleeping itself leads to more sleep difficulties.

WHAT ARE THE SYMPTOMS OF INSOMNIA?

Many people with insomnia experience at least 1 of the following sleep issues:

- Trouble falling asleep at the beginning of the night
- Waking up during the night and taking a long time to fall asleep again
- Waking up early in the morning and being unable to fall back to sleep

Insomnia impacts how people feel and function during the day, including:

- Feeling tired and/or sleepy during the day
- Finding it hard to concentrate and remember things
- Performing poorly at work or school
- Feeling moody or irritable, acting rashly or aggressively
- Lacking energy or motivation
- Making more mistakes or accidents
- Worrying or feeling frustrated about sleep
- Feeling depressed

INSOMNIA SYMPTOMS IMPACT
NIGHTTIME SLEEP AND DAYTIME
MOOD AND FUNCTIONING

HOW IS INSOMNIA DIAGNOSED?

Seeing a **sleep specialist** is recommended, especially for insomnia that has been ongoing for 3 months or longer.

- A healthcare provider will ask questions about symptoms, sleep, health, and wellbeing, and may do a physical exam and other tests to find the potential cause and best treatment plan.
- A healthcare provider may ask people to track their sleep and wake patterns for several days by keeping a **sleep diary** and/or wearing a clinical monitor (**actigraph**).
- A **sleep study** (also called polysomnography) is not required to diagnose insomnia but may be done to rule out other sleep disorders. Stick-on sensors measure breathing, heart rate, brain activity, and body movements while asleep. The study can be done during an overnight stay in a **sleep center/lab** or **at home**. Home testing collects less information but may be more convenient for straightforward cases.

HOW IS INSOMNIA TREATED?

The best choice of treatment for each person with insomnia depends on the type and cause of insomnia, and may include:

- **Cognitive behavioral therapy for insomnia** (CBT-i) is recommended for most people with insomnia. CBT-i addresses the causes of chronic insomnia and helps train the brain and body to be able to sleep naturally. It is typically provided by a clinical psychologist board-certified in Behavioral Sleep Medicine, though other clinicians may also have this expertise. It can be provided in-person, via telehealth or with an app.
- Other **behavioral and cognitive therapies** that help for certain types of insomnia include stimulus control, sleep restriction therapy, paradoxical intention, behavioral experiments, relaxation training, cognitive restructuring, and sleep compression.
- Helpful **lifestyle strategies** include keeping healthy sleep habits (also called sleep hygiene) and relaxation techniques, though these are typically only helpful for mild sleep problems and not chronic insomnia.
- **Social support**, through connecting with other people who have insomnia, can empower people to learn coping strategies.
- **Medications** can affect different types of insomnia differently, and if used incorrectly can make insomnia worse. Therefore all sleep medications, including those available without a prescription, should be used with the advice of a sleep specialist.
 - Prescription medications approved by the FDA for treating insomnia include orexin receptor antagonists, benzodiazepine receptor antagonists, benzodiazepines, melatonin agonists, and heterocyclics. These medications may be helpful if used occasionally; however, if used long-term some of these medications can become less effective and can be habit forming. Some medications can cause complex sleep behaviors such as sleep walking and increase risk of accidents.
 - Some medications for treating other conditions can also help with insomnia, and may be prescribed **'off-label.'**
 - Over-the-counter medications and supplements are not recommended for treating chronic insomnia, including melatonin, diphenhydramine, L-tryptophan, and valerian. These have not been shown to be effective for insomnia.
- **Treating other health issues** that could be contributing to insomnia.

EVEN NON-PRESCRIPTION SLEEP MEDICATIONS SHOULD BE USED WITH A SLEEP SPECIALIST'S SUPERVISION.

NARCOLEPSY

WHAT IS NARCOLEPSY?

Narcolepsy is a chronic neurological condition that impairs the brain's ability to regulate the sleep-wake cycle. It affects 1 in 2,000 people; 200,000 Americans and 3 million people worldwide.

WHAT ARE THE SYMPTOMS OF NARCOLEPSY?

Narcolepsy symptoms vary by person but may include:

- **Excessive daytime sleepiness:** Periods of extreme sleepiness during the day that feel comparable to how someone without narcolepsy would feel after staying awake for 48-72 hours.
- **Cataplexy:** Striking, sudden episodes of muscle weakness usually triggered by strong emotions such as laughter, exhilaration, surprise, or anger. The severity may vary from a slackening of the jaw or buckling of the knees to falling down. The duration may be for a few seconds to several minutes and the person remains fully conscious (even if unable to speak) during the episode.
- **Hypnagogic and hypnopompic hallucinations:** Visual, auditory, or tactile hallucinations upon falling asleep or waking up. These can be frightening and confusing.
- **Sleep paralysis:** The inability to move for a few seconds or minutes upon falling asleep or waking up. It is often accompanied by hypnagogic or hypnopompic hallucinations.
- **Disrupted nighttime sleep:** Unlike public perceptions, people with narcolepsy do not sleep all the time. Timing of sleepiness is "off" with narcolepsy so one may fight sleepiness during the day but struggle to sleep at night.

★ UNLIKE PUBLIC PERCEPTIONS,
PEOPLE WITH NARCOLEPSY
DO NOT SLEEP ALL THE TIME. ★

TYPES OF NARCOLEPSY

There are two forms of narcolepsy: type 1 narcolepsy with cataplexy, and type 2 narcolepsy without cataplexy. Recent research suggests that type 1 narcolepsy with cataplexy is caused by a lack of hypocretin (also called orexin), a key neurotransmitter that helps sustain alertness and regulate the sleep-wake cycle. Less is known about type 2 narcolepsy without cataplexy.

HOW IS NARCOLEPSY DIAGNOSED?

Diagnosis typically relies on a **24-hour sleep study** that includes a nighttime portion (polysomnogram) and daytime nap portion (multiple sleep latency test). The diagnosis is mainly based on how quickly and frequently one's brain enters rapid eye movement sleep (REM)/dream sleep during these tests.

HOW IS NARCOLEPSY TREATED?

There is currently no cure for narcolepsy. Treatment for symptom management varies widely by person and it often takes a long time to find the right combination of treatments.

Treatments may include:

- **Nighttime or histamine-directed medications** to decrease excessive daytime sleepiness and cataplexy
- **Wake-promoting or stimulant medications** to increase alertness
- **Antidepressant medication** to decrease cataplexy
- Scheduled daytime **naps**

Coping strategies vary widely by person but may include:

- **Social support** such as meet-up groups or social media
- **Improvement in general health** and wellness through sleep hygiene, diet, and fitness

NARCOLEPSY AWARENESS

Because of low awareness (even among physicians) and misperceptions, there is an average of **8 to 15 years** between narcolepsy symptom onset and diagnosis.

It's estimated that **the majority of people with narcolepsy are currently undiagnosed or misdiagnosed**. Common misdiagnoses include epilepsy, depression, and schizophrenia.

PUBLIC MISPERCEPTIONS OF
NARCOLEPSY LEAD TO DELAYED
DIAGNOSIS AND TREATMENT.

If you suspect that you or a loved one could have narcolepsy, it is important to consult an AASM board-certified sleep medicine doctor. To find a local sleep specialist or accredited sleep center, visit www.sleepeducation.org.

KLEINE-LEVIN SYNDROME

WHAT IS KLEINE-LEVIN SYNDROME?

Kleine-Levin Syndrome (KLS) is a rare disorder of hypersomnolence. People with KLS experience episodes of excessive sleepiness (sometimes sleeping up to 20 hours a day) that last for days or weeks, with normal sleep and wake patterns in between.

WHAT ARE THE SYMPTOMS OF KLEINE-LEVIN SYNDROME?

Episodes of excessive sleepiness or **sleep episodes** can last days or weeks, and can be weeks or months apart (1-12 times per year).

In a subtype of KLS called menstrual-related hypersomnia, sleep episodes happen for approximately a week during a person's period. The symptoms of KLS can be distressing and have a negative impact on work and social life.

Before a sleep episode, people with KLS may have headaches and feel very tired. During sleep episodes, people with KLS may experience:

- Sleeping up to 20 hours per day, only waking up to eat and use the bathroom
- Binge eating, leading to weight gain
- Higher sex drive than usual
- Red face and/or sweating a lot
- Irritability and/or aggression
- Depression
- Feeling detached from reality
- Feeling confused or disoriented
- Hallucinations

KLS SYMPTOMS CAN HAVE
DEBILITATING IMPACTS ON SCHOOL,
WORK, AND RELATIONSHIPS.

HOW IS KLEINE-LEVIN SYNDROME DIAGNOSED?

Seeing a **sleep specialist** is recommended, because KLS is rare and may initially be mistaken for other conditions. The sleep specialist will do tests to check for other potential causes of the sleep episodes, including other sleep disorders, medical conditions, medications, mental health issues, or substance use.

The sleep specialist will ask patients about their symptoms and sleep. They may also interview parents or others who have seen an episode. Some healthcare providers may ask people to track their sleep and wake patterns for several days by keeping a **sleep diary** or wearing a smartwatch.

To check for other sleep disorders, sleep tests are done in a sleep center/lab using stick-on sensors that measure breathing, heart rate, brain activity, and body movements. These could include:

- An **overnight sleep study** (also called polysomnography), which measures a full night's sleep.
- A **multiple sleep latency test**, which measures how a person sleeps during the day after an overnight sleep study. The person is asked to nap for around 20 minutes every 2 hours.
- A **maintenance of wakefulness test**, which measures how long a person can stay awake in a dark, quiet, comfortable room. It is done during the day after a full night's sleep.

HOW IS KLEINE-LEVIN SYNDROME TREATED?

KLS treatment is focused on managing a person's specific symptoms. There is no cure for KLS but symptoms often improve over several years.

- **Wake-promoting medications** are not specifically indicated for KLS, but may help people with KLS stay awake during episodes and go to work or school. However, they may also increase irritability.
- For menstrual-related hypersomnia, **hormonal birth control medication** may prevent sleep episodes.
- **Social support** from people with KLS or other hypersomnias can empower people with KLS and their families to live well.

★ SOCIAL SUPPORT IS CRITICAL FOR
ADJUSTING TO LIFE WITH KLS
AND OTHER SLEEP DISORDERS. ★

RESTLESS LEGS SYNDROME

WHAT IS RESTLESS LEGS SYNDROME?

Restless legs syndrome (RLS, also called Willis-Ekbom disease) is a neurological sleep disorder that involves uncomfortable feelings in the legs that can make it difficult to sleep. RLS affects up to 8% of people in the US and is more common in women and people over 45 years old, but it can develop at any age. The causes vary between people, and can include low iron levels, certain medications, other health conditions (e.g. diabetes, kidney failure, Parkinson's disease), pregnancy, genetics, or unknown causes. Many people with RLS also experience twitching legs or arms while they are asleep – this is a related condition called periodic limb movements of sleep (PLMS).

WHAT ARE THE SYMPTOMS OF RESTLESS LEGS SYNDROME?

- A strong urge to move legs (and/or sometimes arms) that is difficult or impossible to resist
- An uncomfortable feeling in the legs that people with RLS have described as a creeping, crawling, tingling, burning, throbbing, or itching sensation inside the legs
- Symptoms are worse when resting, such as sitting or lying down to sleep
- Symptoms get better while walking, stretching or moving around
- Symptoms are worse in the evening or night
- Symptoms make it difficult to fall asleep and to stay asleep
- Getting less sleep because of RLS can lead to feeling excessively sleepy during the day, difficulty concentrating, irritability, anxiety, or depression

RLS CAN CAUSE DAYTIME SLEEPINESS,
DIFFICULTY CONCENTRATING,
IRRITABILITY, ANXIETY, OR DEPRESSION

HOW IS RESTLESS LEGS SYNDROME DIAGNOSED?

A healthcare provider will ask questions about symptoms, sleep and medical history and family history of RLS, and the impact RLS has on daily life. Additional tests may include:

- **Blood tests**, including measuring iron levels
- Keeping a **diary** of symptoms, potential triggers, and sleep habits for 1-2 weeks
- A **sleep study** is not required to diagnose RLS but may be done to rule out other sleep disorders. A sleep study uses stick-on sensors to measure breathing, heart rate, brain activity, and body movements while asleep. The study can be done during an overnight stay **in a sleep center/lab** or **at home**. Home testing collects less information but may be more convenient for straightforward cases.

HOW IS RESTLESS LEGS SYNDROME TREATED?

- **Treating other health issues** that may be causing a person's RLS.
- Helpful **copng strategies** to reduce RLS symptoms include keeping healthy sleep habits, getting moderate daily exercise, eating well, and avoiding caffeine, alcohol, and nicotine. Symptoms can be relieved by moving or stretching legs, a hot bath, leg massage, and applying cold or hot packs.
- **Medications** that increase dopamine levels in the brain are approved by the FDA for RLS, however these become less effective after using them for a while. Some medications typically used to treat seizures are also FDA-approved for RLS. Research suggests that some medications that are FDA-approved for other conditions can be effective for RLS. Healthcare providers may prescribe these "off-label," including opioids, which can be helpful for severe symptoms but can be habit-forming. Iron supplements may also be prescribed if iron/ferritin levels are low.
- **Social support** from other people with RLS can help people manage their RLS.

HEALTHY COPING STRATEGIES
AND SOCIAL SUPPORT CAN HELP
PEOPLE MANAGE THEIR RLS.

IDIOPATHIC HYPERSOMNIA

WHAT IS IDIOPATHIC HYPERSOMNIA?

Idiopathic hypersomnia (IH) is a chronic neurological sleep disorder. People with IH are very sleepy despite getting normal or longer amounts of sleep, but the exact cause is not known.

WHAT ARE THE SYMPTOMS OF IDIOPATHIC HYPERSOMNIA?

- Trouble staying awake and alert during the day (excessive daytime sleepiness)
- Sleeping longer than average (more than 11 hours per 24 hours, typically 12-14 hours)
- Extreme difficulty waking from sleep
- Feeling very groggy, confused, or disoriented when waking up from an overnight sleep or nap (called sleep inertia or sleep drunkenness), which may last for hours after waking.
- Not feeling refreshed even after sleeping an average amount (7-9 hours) or after a nap
- Falling asleep accidentally, e.g. while driving or working
- Difficulty coping with social life, work, or study because of sleepiness (can also lead to depression)
- Some people have trouble with memory and brain fog
- Some people with IH also experience headaches, dizziness, or cold hands and feet

BECAUSE OF LOW AWARENESS,
IH SYMPTOMS ARE OFTEN
UNDIAGNOSED OR MISDIAGNOSED.

HOW IS IDIOPATHIC HYPERSOMNIA DIAGNOSED?

Diagnosis usually involves medical tests to check for other potential causes of sleepiness, such as narcolepsy or other sleep disorders. **Seeing a sleep specialist is recommended.**

- A healthcare provider will ask questions about symptoms and sleep. Some healthcare providers may ask people to monitor their sleep and wake activity for several days by keeping a **sleep diary** or wearing a clinical device (e.g. an **actigraph**).
- To check for other sleep disorders, an overnight **sleep study** (also called polysomnography) is done followed by a **multiple sleep latency test** the next day, where the person is asked to nap for 20 minutes every 2 hours. People who fall asleep very quickly but don't enter REM sleep may have idiopathic hypersomnia. Both tests are done in a sleep center/lab, with stick-on sensors that measure breathing, heart rate, brain activity, and body movements while asleep.

HOW IS IDIOPATHIC HYPERSOMNIA TREATED?

As there is currently no cure for IH, the goal of treatment is to live well by managing alertness.

- **Medications** may be prescribed to help people feel more alert and active when awake and to sleep more deeply at night, including stimulants, non-stimulant wake-promoting agents, oxybates, antidepressants, and medications that target the GABA system. Only one medication is approved by the FDA specifically for IH, the other medications are known to be effective for treating sleepiness in other disorders such as narcolepsy and are used “off-label” to treat IH.
- **Treating other sleep disorders** and avoiding certain medications is helpful to reduce other potential causes of sleepiness.
- Helpful **lifestyle strategies** include keeping healthy sleep habits, getting light in the morning, using more than one alarm, asking friends and family to help with waking for appointments, and avoiding driving when sleepy.
- **Counselors** can help people navigate the challenges of living with IH.
- **Social support** from patient organizations can help people with IH and their families live well with IH.

★ PROPER DIAGNOSIS, TREATMENT,
AND SOCIAL SUPPORT CAN HELP
PEOPLE LIVE WELL WITH IH. ★

CIRCADIAN DISORDERS

WHAT ARE CIRCADIAN RHYTHM SLEEP WAKE DISORDERS?

People with a circadian rhythm sleep wake disorder (CRSWD) have difficulty sleeping and being awake at normal times of night and day. Generally, people sleep at night and feel alert during the day, in time with the daily 24-hour cycle of sunlight and darkness (also called the body's circadian rhythm or body clock). In some people sleep gets out of sync with conventional times because of genetic differences, changes in habits or timezones, or exposure to light at unusual times, leading to CRSWDs. It is uncertain how many people have a CRSWD, with some estimates ranging from 3% to 16%.

WHAT ARE THE SYMPTOMS OF CIRCADIAN RHYTHM SLEEP WAKE DISORDERS?

- **Delayed sleep-wake phase:**

- A pattern of falling asleep and waking up hours later than is typical (extreme "night owl")
- Difficulty falling asleep in the evening and waking up in the morning
- If sleeping at preferred times, sleep is normal

- **Advanced sleep-wake phase:**

- A pattern of falling asleep and waking up earlier hours than is typical (extreme "early bird")
- Feeling sleepy or falling asleep in the late afternoon or early evening
- Waking up alert early in the morning and not being able to go back to sleep
- If sleeping at preferred times, sleep is normal

- **Non-24 sleep-wake rhythm:**

- If left to sleep naturally, bedtime and wake time drift later each day
- Sleep times that seem to jump around, because over several weeks the sleep period will drift in and out of sync with other people, progressing from night to morning, to afternoon, to night, and so on.
- Most common in people who are blind, but can also affect sighted people

- **Irregular sleep-wake rhythm:**

- No regular pattern to the timing of sleep and wakefulness
- Sleep is broken into 3 or more naps across a 24-hour period

- **Shift work disorder:**

- Difficulty adjusting to shift work schedules, leading to health issues and social challenges

- **Jet lag:**

- Temporary difficulty adjusting to rapid travel across more than 2 time zones
- For people who travel often, jet lag may become chronic and benefit from specialist treatment

MANY PEOPLE LIVING WITH A CRSWD EXPERIENCE WORK, RELATIONSHIP, AND MENTAL HEALTH CHALLENGES.

Some symptoms are common across CRSWDs:

- People with CRSWDs may experience sleep deprivation, especially if trying to maintain socially conventional sleep schedules. This can lead to symptoms when they are awake including fatigue, sleepiness, difficulty concentrating, headaches, nausea, and moodiness.
- They may use substances to fall asleep (eg alcohol or sleeping pills) and stay awake (eg. coffee or stimulants) at societally normal times, that can make their sleep worse.
- CRSWDs can be misinterpreted as signs of insomnia or depression.
- CRSWDs can make it difficult to maintain relationships and meet work, school and social responsibilities.

HOW ARE CIRCADIAN RHYTHM SLEEP WAKE DISORDERS DIAGNOSED?

Seeing a **sleep specialist** is recommended for people who are experiencing health problems or challenges in work, school, or social life related to their sleep timing. The sleep specialist will ask patients about their symptoms and sleep and do a medical and neurological exam.

- They may ask people to track their sleep and wake patterns for several days or weeks by keeping a **sleep diary** and/or wearing an **actigraph** (a medical device that looks like a smartwatch).
- A **sleep study** (also called polysomnography) is not required to diagnose CRSWDs but may be done to check for other sleep disorders. Stick-on sensors measure breathing, heart rate, brain activity, and body movements while asleep. The study can be done during an overnight stay **in a sleep center/lab** or **at home**. Home testing collects less information but may be more convenient for straightforward cases.

HOW ARE CIRCADIAN RHYTHM SLEEP WAKE DISORDERS TREATED?

The best choice of treatments for each person depends on the type and cause of CRSWD. They all revolve around getting sleep timing more in sync with society and the environment.

- For some people, **adapting lifestyle** to fit work/school/social schedules around their preferred sleep schedule is enough to resolve their CRSWD-related issues (e.g. evening hobbies and working late shifts for people with DSPD). Others may need additional treatments.
- **Treating other health conditions**, including sleep disorders, that could be contributing to symptoms.
- **Behavioral therapies**, including education, counseling, and cognitive behavioral therapy, can help with keeping healthy sleep habits and training the brain and body to sleep on a regular schedule.
- **Social support**, through connecting with other people who have a CRSWD and their families, can empower people to learn helpful strategies for living well.
- For sighted people and certain types of blindness, carefully timed **bright light therapy** can help to adjust and maintain sleep-wake timing. Scheduling other behaviors such as eating and exercise can also help.
- **Melatonin** supplements and medications that affect melatonin receptors can help to adjust sleep timing if used at appropriate doses and times.

PARASOMNIAS

WHAT ARE PARASOMNIAS?

Parasomnias are unusual events or experiences that happen while falling asleep, sleeping, or waking up. Parasomnias can range from simple experiences and actions like waking up in the middle of the night in a disoriented state or groaning while asleep, to complex behaviors such as sleep walking and eating and vivid experiences like nightmares and hallucinations. Most people experience a parasomnia in their life, especially as children. They can be inherited, related to stress, poor sleep, or other medical conditions. They may not require treatment unless they interfere with a person's health and safety.

WHAT ARE THE SYMPTOMS OF PARASOMNIAS?

Each parasomnia has unique symptoms:

- **Sleep walking (somnambulism):** getting up from bed and walking around while asleep
- **Sleep terrors (night terrors):** sitting or leaping up in intense fear or screaming, typically without remembering the dream
- **Nightmares:** terrifying dreams that may make it difficult to get a good night's sleep
- **Confusional arousals:** acting in a strange and confused way on waking up
- **Sleep talking (somniloquy) or groaning (catathrenia):** talking, groaning, or grunting while asleep
- **Sleep-related eating disorder:** binge eating, or eating unusual substances while asleep
- **Sleep hallucinations:** imaginary events that seem very real when falling asleep or waking up (can involve sight, sound, touch, taste, smell, or movement and are often very frightening)
- **Sleep paralysis:** being unable to move when falling asleep or waking up
- **REM sleep behavior disorder:** acting out dreams
- **Exploding head syndrome:** waking up to a sudden imaginary loud noise or explosion
- **Bedwetting (sleep enuresis):** urinating by accident while asleep
- **Sexsomnia:** Carrying out sexual behaviors while asleep

Some symptoms that may be common across parasomnias include:

- Difficulty sleeping through the night
- Waking up confused or disoriented
- Being tired during the day
- Finding cuts or bruises and not remembering how they were caused
- Movements, vocalizations, or activities that the person doesn't remember when told by a roommate

HOW ARE PARASOMNIAS DIAGNOSED?

Seeing a **sleep specialist and/or neurologist** is recommended. They will ask questions about symptoms and sleep, ideally with the help of a partner or roommate who has witnessed the behavior, if available. They will also do a physical and neurological exam.

- They may ask people to track their sleep and wake patterns for several days or weeks by keeping a **sleep diary** and/or wearing an **actigraph** (a medical device that looks like a smartwatch).
- To diagnose a parasomnia and to check for other sleep disorders, an overnight **sleep study** (also called polysomnography) may be done **in a sleep center/lab**. It uses video and stick-on sensors to monitor body movements, brain activity, breathing, and heart rate.
- Some specialists may also request a **multiple sleep latency test**, which measures how a person sleeps during the day after an overnight sleep study. The person is asked to nap for around 20 minutes every 2 hours.

HOW ARE PARASOMNIAS TREATED?

Parasomnias may not need treatment, especially in children, unless they are frequent or could result in injury. The best choice of treatments for each person depends on the type and cause of parasomnia.

- Depending on the parasomnia, helpful **lifestyle strategies** could include safety measures (e.g., padding hard furniture, storing knives securely, locking windows or cupboards), avoiding caffeine and alcohol in the evening, and developing healthy sleep habits.
- **Treating other health conditions**, including sleep disorders and mental health issues that could be contributing to symptoms. In some cases, certain medications may provoke parasomnias, so stopping those medications may be the appropriate treatment.
- **Behavioral therapies**, including education, counseling, and cognitive behavioral therapy, can help with keeping healthy sleep habits and treating related mental health conditions.
- **Social support**, through connecting with other people who have parasomnia and their families, can empower people to learn helpful strategies for living well. It can be helpful for parents or roommates to learn how to react when a person is experiencing parasomnia symptoms.
- **Medications** used to treat parasomnias in adults include benzodiazepines, tricyclic antidepressants, alpha blockers, and melatonin.

★ LOVED ONES AND ROOMMATES
CAN LEARN HELPFUL RESPONSES
TO PARASOMNIA SYMPTOMS. ★

MOVEMENT DISORDERS

WHAT ARE SLEEP-RELATED MOVEMENT DISORDERS?

Sleep-related movement disorders are conditions that cause unusual movements that happen while falling asleep, sleeping, or waking up. They can be inherited, related to stress, poor sleep, or other medical conditions, or due to unknown causes. They may not require treatment unless they interfere with a person's health and safety.

WHAT ARE THE SYMPTOMS OF SLEEP-RELATED MOVEMENT DISORDERS?

Sleep-related movement disorders can make it difficult to fall asleep, stay asleep, or to get restful sleep. This can lead to feeling excessively sleepy during the day, difficulty concentrating, irritability, anxiety, or depression. Each disorder has unique symptoms:

- **Bruxism:** grinding or clenching teeth while asleep, leading to jaw, mouth and face pain, headaches, and tooth damage
- **Sleep leg cramps:** sudden, intense, painful leg muscle contractions while asleep or falling asleep
- **Restless legs syndrome:** an uncomfortable sensation in the legs and irresistible urge to move them, when lying down to sleep
- **Periodic limb movements (PLMS):** repeated leg and/or arm twitches while asleep
- **Sleep rhythmic movement:** regular body movements while drowsy or asleep, including body rocking, head banging or head rolling
- **Sleep starts:** sudden, strong body twitch when falling asleep (aka hypnagogic jerks) or waking up (aka hypnic jerks), sometimes with a feeling of falling, or a sensory flash

HOW ARE SLEEP-RELATED MOVEMENT DISORDERS DIAGNOSED?

Seeing a **sleep specialist and/or neurologist** is recommended. They will ask questions about symptoms and sleep, ideally with the help of a partner or roommate who has witnessed the behavior, if available. They will also do a physical and neurological exam.

- They may ask people to track their sleep and wake patterns for several days or weeks by keeping a **sleep diary** and/or wearing an **actigraph** (a medical device that looks like a smartwatch).
- To diagnose a sleep-related movement disorder and to check for other sleep disorders, an **overnight sleep study** (also called polysomnography) may be done **in a sleep center/lab**. It uses video and stick-on sensors to monitor body movements, brain activity, breathing, and heart rate.
- If there's reason to suspect another potential sleep disorder, some specialists may also request a **multiple sleep latency test**, which measures how a person sleeps during the day after an overnight sleep study. The person is asked to nap for around 20 minutes every 2 hours.

HOW ARE SLEEP-RELATED MOVEMENT DISORDERS TREATED?

Sleep-related movement disorders may not need treatment, especially in children, unless they are frequent, could result in injury, or make it difficult to get a good night's sleep. The best choice of treatments for each person depends on the type and cause of the disorder.

- Depending on the disorder, helpful **lifestyle strategies** could include safety measures (e.g. padding sharp bedroom furniture), avoiding caffeine and alcohol in the evening, reducing stress, staying hydrated, daily exercise and stretching, massage or hot showers before bed, and loosening tucked sheets.
- For bruxism, **mouth guards** can protect teeth.
- **Treating other health conditions**, including sleep disorders and mental health issues that could be contributing to symptoms.
- **Social support**, through connecting with other people who have a sleep-related movement disorder and their families, can empower people to learn helpful strategies for living well.
- **Medications** used to treat sleep-related movement disorders in adults include iron supplements, medications typically used to treat anxiety, depression, or seizures, medications that increase dopamine levels in the brain, and opioids.

SOCIAL SUPPORT CAN BE HELPFUL
FOR MANAGING SLEEP-RELATED
MOVEMENT DISORDERS.

REM BEHAVIOR DISORDER

WHAT IS REM SLEEP BEHAVIOR DISORDER?

REM sleep behavior disorder (RBD) is a condition in which people act out their dreams, sometimes injuring themselves or their bed partners. During sleep we cycle through several stages, and most vivid dreaming happens during the REM sleep stage. During REM sleep, the brain usually keeps muscles completely relaxed (paralyzed), but in people with REM sleep behavior disorder (RBD) this process is disrupted, allowing people to act out their dreams.

There are several types of RBD. RBD can be an isolated neurological disorder, or related to another medical condition such as Parkinson's disease or dementia with Lewy bodies - this type is more common in people over 50 years old. In people less than 50 years old RBD is more commonly a side effect of medications, such as SSRI antidepressants, caused by brain lesions affecting the brain regions that control REM sleep, or associated with narcolepsy.

WHAT ARE THE SYMPTOMS OF REM SLEEP BEHAVIOR DISORDER?

People with RBD may look like they are acting out their dreams, including:

- Body twitches and jerks while asleep
- Vigorous movements like flailing, grabbing, kicking, punching, jumping, or leaping out of bed while they are still asleep
- Talking, shouting, swearing, or calling out while asleep
- Remembering vivid dreams that match their actions when they wake up

People with RBD can injure themselves or their bed partner and disturb their bed partner's sleep. Although it is possible for people without RBD to occasionally experience some of these symptoms, people with RBD generally have them more often and get worse over time, increasing the risk of injury.

HOW IS REM SLEEP BEHAVIOR DISORDER DIAGNOSED?

Seeing a **sleep specialist and/or neurologist** is recommended. They will ask questions about symptoms and sleep, ideally with the help of a partner or roommate who has witnessed the behavior, if available. They will also do a physical and neurological exam.

- To diagnose RBD and to check for other sleep disorders, an **overnight sleep study** (also called polysomnography) is done in a sleep center/lab. It uses video and stick-on sensors to monitor body movements, muscle tone, brain activity, breathing, and heart rate.
- If there's reason to suspect another potential sleep disorder, some specialists may also request a **multiple sleep latency test**, which measures how a person sleeps during the day after an overnight sleep study. The person is asked to nap for around 20 minutes every 2 hours.

HOW IS REM SLEEP BEHAVIOR DISORDER TREATED?

The best choice of treatments for each person with RBD depends on the type and cause of RBD, and co-existing medical conditions, and may include:

- **Bedroom safety precautions** to reduce the risk of injury, such as removing weapons from the bedroom, moving the bed away from windows, placing a large object like a dresser in front of windows, moving objects that could cause injury away from the bed like lamps, padding hard furniture, putting a soft rug by the bed, and having a barrier (e.g., pillows) between the person with RBD and their bed partner, or the bed partner sleeping in a separate bed.
- **Discussing discontinuing medication** that may be causing RBD symptoms with your doctor.
- **Treating other sleep disorders** that can make RBD symptoms worse.
- Helpful **lifestyle strategies** include keeping healthy sleep habits (also called sleep hygiene) and learning about RBD.
- **Social support**, through connecting with other people who have RBD and their families, can empower people to understand RBD and learn strategies to live well with RBD.
- **Regular monitoring for symptoms** that could be a sign of other neurological disorders, such as tremors.
- **Medications** may be prescribed for people with isolated RBD or secondary RBD due to a medical condition, including clonazepam and melatonin. Pramipexole may be helpful for people with isolated RBD. Rivastigmine can be helpful in people who also have mild cognitive impairment or Parkinson's disease.

PEOPLE WITH REM SLEEP
BEHAVIOR DISORDER NEED A
SAFE SLEEPING ENVIRONMENT.