narcolepsy

nerd alert

TYPES OF NARCOLEPSY TOOLKIT

Created by:

projectsleep

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 navigating narcolepsy. Project Sleep created this toolkit as part of the **Narcolepsy Nerd Alert** series.

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

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

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.

MEET OUR GUEST

Dr. Chad Ruoff, MD, received his Doctor of Medicine degree from Wright State University School of Medicine. He also completed a residency in Internal Medicine at Baylor College of Medicine, and a fellowship in Sleep Medicine at Stanford University.

Dr. Ruoff is a sleep medicine specialist at Mayo Clinic, where he enjoys evaluating and treating all sleep disorders, such as sleep apnea, narcolepsy and idiopathic hypersomnia, restless legs syndrome, parasomnias, and circadian rhythm disorders. He has authored and coauthored numerous publications on various topics within sleep medicine and is also active in education, speaking at national conferences and providing mentorship to medical students.

Dr. Ruoff is a member of the American Academy of Sleep Medicine (AASM) Taskforce on The Use of the Multiple Sleep Latency Test and Maintenance of Wakefulness Test, and serves on the Medical Board of Directors for the Hypersomnia Foundation.

MEET THE HOST

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

TYPES OF NARCOLEPSY

What distinguishes narcolepsy type 1, type 2, and idiopathic hypersomnia? Can my diagnosis change?

On June 29, 2022, sleep medicine specialist Dr. Chad Ruoff joined host Julie Flygare to share his expertise on what distinguishes narcolepsy type 1, narcolepsy type 2, and idiopathic hypersomnia.

In this Narcolepsy Nerd Alert, Dr. Ruoff explains how specialists evaluate sleepiness and breaks down the diagnostic criteria for these conditions. He also shares his own research about challenges in testing for narcolepsy, and thoughts on how the diagnostic process might be improved in the future.

This toolkit aims to outline the symptoms & characteristics, tests available to specialists, and diagnostic criteria associated with each condition. While everyone's experience is unique, the descriptions in this toolkit reflect the opinions of narcolepsy experts including Dr. Ruoff, which are the basis of training for sleep specialists around the world.

- Watch the Types of Narcolepsy video: https://youtu.be/gdD0nAypIdE
- Learn more about the Narcolepsy Nerd Alert Series: https://project-sleep.com/narcolepsy-nerd-alert/

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

Feeling extra nerdy?
Check the appendix when you see this [#].

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WHY AM I SO TIRED?

Excessive sleepiness during the daytime even after adequate sleep is called hypersomnolence.

- People who struggle to stay awake through the day may have a **central disorder of hypersomnolence,** also called a central nervous system (CNS) hypersomnia.
- Hypersomnolence could be due to:
  - Narcolepsy type 1 (narcolepsy with cataplexy)
  - Narcolepsy type 2 (narcolepsy without cataplexy)
  - Idiopathic hypersomnia
  - An underlying condition that is not a sleep disorder. For example, someone could be unable to stay awake through the day because of a condition like lupus, which causes extreme fatigue.
- Narcolepsy was first identified when doctors discovered that some people enter REM sleep, the sleep stage when dreams occur, much faster than the average person.
- In 1999 researchers showed that people with narcolepsy type 1 (NT1) are deficient in orexin, a neurotransmitter which regulates the sleep-wake cycle. See our Science of Narcolepsy toolkit for more information (link in resources section).

Should I tell my doctor I'm struggling with sleepiness?

Feeling sleepy all the time or fighting to stay awake throughout the day is not normal. Of course, inadequate sleep and sleep deprivation will cause anyone to feel tired during the day. However, if you consistently get adequate sleep and still struggle with sleepiness, or if you are regularly unable sleep despite your best efforts, you may have a sleep disorder and you should talk to your doctor. If there are no other apparent causes of your sleepiness or other difficulties with sleep, your doctor may refer you to a sleep specialist for testing and diagnosis.

> Before doctors refer a patient for testing in the sleep clinic, they should ask about other symptoms to be sure there's not another explanation for sleepiness or fatigue.
>
> - Dr. Ruoff

NARCOLEPSY SYMPTOMS

What symptoms help doctors identify narcolepsy?

The **Narcolepsy Pentad** is typically used to identify narcolepsy. While you may be familiar with these symptoms, the terms for them can vary. See the glossary at the end of this toolkit for alternate terminology and definitions.

- **Excessive daytime sleepiness (EDS)**: periods of extreme sleepiness throughout the day that feel comparable to how a person without narcolepsy would feel after staying awake for 48–72 hours.
- **Cataplexy:** sudden loss of muscle tone triggered by intense emotions, usually positive ones such as laughter or excitement, but sometimes fear, surprise or anger.
  - Cataplexy usually lasts from seconds up to a few minutes, and you remain fully conscious (even if unable to speak).
  - People with narcolepsy type 2 (NT2) do not experience cataplexy.
- **Sleep-related hallucinations:** visual, auditory, or tactile hallucinations upon falling asleep or waking up. These can be frightening and confusing.
  - Hallucinations are called hypnagogic hallucinations if they happen as you fall asleep and hypnopompic hallucinations if they occur upon waking.
- **Sleep paralysis:** temporary inability to move or speak while falling asleep or upon waking.
  - These episodes are usually brief — lasting a few seconds or minutes — but can be frightening.
  - People without sleep disorders can experience sleep paralysis and sleep-related hallucinations. Many people experience these at some point in their lives, usually during periods of high stress or poor sleep. For people with narcolepsy, these are much more frequent and consistent over time.
- **Disrupted nighttime sleep:** increased awakenings, arousals, sleep stage transitions, and light sleep (Maski et al., 2020).
  - This might feel like drifting in and out of sleep all night.
  - For people with narcolepsy, the timing of sleepiness is not properly regulated. A person with narcolepsy may fight sleepiness during the day but struggle to sleep at night.

IH SYMPTOMS

What symptoms help doctors identify idiopathic hypersomnia?

- **Excessive daytime sleepiness (EDS)**: persistent sleepiness throughout the day that occurs despite adequate or even prolonged nighttime sleep.

> It's more than just feeling tired, it feels like someone has nailed something heavy to my face between my eyebrows, and in order to open my eyes I need to lift it with my eyelids.
>
> - Amy

While EDS characterizes idiopathic hypersomnia, doctors and people living with IH commonly describe some other symptoms as well:

- **Prolonged nighttime sleep:** Many people with IH sleep more than 11 hours out of every 24.
- **Unrefreshing naps:** Even long naps result in feeling no better or worse upon waking than when falling asleep.
- **Sleep inertia:** feelings of grogginess and sleepiness that occur upon awakening, which can result in impaired alertness and may interfere with the ability to perform mental or physical tasks. A severe form of sleep inertia that is common with IH is called sleep drunkenness.
- **Difficult sleep-to-wake transition:** While people without sleep disorders may wake up and briefly want to return to sleep, in people with idiopathic hypersomnia, this sleep-to-wake transition is much more difficult and prolonged. This may result in a need for multiple alarm clocks or other extreme measures.

> If someone doesn't wake me up, I can sleep for 18 or more hours. The only thing that can actually get me on my feet is my arch nemesis... a full bladder!
>
> - Elisabeth

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DIAGNOSTIC TOOLS

How do sleep specialists assess sleep-related symptoms?

- Discussing the symptom **history** is the starting point.
  - This can be an emotionally challenging part of the process. It can be difficult to remember specifics like when certain symptoms first appeared, especially if you've been experiencing them every day for years. Dr. Ruoff strongly encourages patients to bring a family member or other supporter to the first consultation, if possible.
- **Questionnaires** are often used to quantify sleepiness and other symptoms. The most commonly used scale is the Epworth Sleepiness Scale, which asks you to report the likelihood of falling asleep in various situations (Johns, 1991).
  - The results of this assessment can't be easily compared between patients but can indicate if your sleepiness has changed over time. Dr. Ruoff says, "Subjective scales have their limitations, but they're important."
- Your doctor may ask you to fill out a **sleep log** each day to document specific sleep and wake habits over a period of time.
  - This is something you can do on your own if you suspect you may have a sleep disorder.
- **Actigraphy** allows the doctor to get an objective measurement of your sleep schedule over a period of time. A watch-like device called an actigraph is worn on the non-dominant wrist, usually for one to two weeks, and measures activity through light and movement.
  - Actigraphy data can be helpful for assessing circadian rhythm disorders such as delayed sleep phase disorder and insomnia. Dr. Ruoff believes actigraphy is a useful tool in diagnosing sleep disorders and could be used more often.

Could a fitness tracker be useful in diagnosing hypersomnia?

Dr. Ruoff says, "That's going to vary widely from provider to provider. You can present it to your specialist." This data can show time spent in bed vs. time sleeping, and differences in sleep patterns across the week and weekend.

> Devices such as fitness trackers may provide useful data, but need more rigorous testing for FDA clearance and approval. For diagnosis, sleep time has to be measured by a recognized, medical-grade actigraphy device.
>
> - Dr. Ruoff

DIAGNOSTIC TOOLS

How do specialists diagnose narcolepsy type 1, type 2, and IH?

- The **overnight sleep study**, called a nocturnal polysomnogram (PSG), is conducted in a sleep lab. A trained technician places sensors and observes your sleep to monitor many aspects of your sleep throughout the night.
  - Data from this test is helpful in ruling out sleep apnea and looking for abnormal sleep architecture. Dr. Ruoff says, "We look closely to see if there's a sleep onset REM period (SOREMP), where someone might go into dream sleep very quickly."

- The **multiple sleep latency test** (MSLT) is the most common way to measure sleepiness throughout the day. This test takes place in a sleep lab and consists of a series of five naps and questions about these naps such as: Did you fall asleep during each nap time? If you did, how long did it take you to fall asleep? If you fell asleep, did you go into REM sleep? Similarly to an overnight sleep study, sensors and monitoring are used to measure various aspects of your sleep during the naps.
  - Dr. Ruoff reminds us that the MSLT should always follow an overnight sleep study in order for the results to be valid.

- A **blood test for HLA DQB1*06:02** can be helpful because almost every person with NT1 has this version of the gene[1]. However, this test alone cannot diagnose NT1 because people in the general population, i.e. people without narcolepsy, can carry HLA DQB1*06:02[2].
  - Especially if you are not sure about cataplexy, this simple blood test can offer a clue that strengthens a diagnosis of NT1.

- If the HLA test is positive, you might talk to your doctor about the pros and cons of a **cerebrospinal fluid (CSF) orexin test**. This test analyzes the fluid that surrounds your brain and spine, and a very low orexin concentration indicates NT1.
  - This test is not commonly used in the US, as it involves a lumbar puncture and is considered a painful and invasive procedure, but it is commercially available[3].

> In terms of advocating for yourself, it is important to know what tests are available. If you're uncertain about your diagnosis, make sure you've engaged your healthcare providers to see if one or more of these tests would be helpful in your situation.
>
> - Dr. Ruoff

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DIAGNOSTIC CRITERIA

What criteria do doctors use to diagnose narcolepsy and idiopathic hypersomnia?

HYPERSOMNOLENCE

- Defined as "daily periods of irrepressible need to sleep or daytime lapses into sleep occurring for at least three months"
- Is associated with all central disorders of hypersomnolence

CATAPLEXY

- Reported by patient
- Is associated with NT1*

MEAN SLEEP LATENCY (MSL)

- How long it takes to fall asleep, on average
- Measured by the MSLT
- A short MSL—8 minutes or less—indicates a central disorder of hypersomnolence.

SLEEP ONSET REM PERIODS (SOREMPS)

- If REM sleep occurs at the onset of sleep, this is called a sleep onset REM period (SOREMP).
- SOREMPS are measured on the overnight sleep study and MSLT.
- Total number of SOREMPS on the overnight sleep study and MSLT is a differentiating factor between narcolepsy and IH.

CEREBROSPINAL FLUID (CSF) OREXIN CONCENTRATION

- Also called CSF hypocretin-1 concentration
- Measured by spinal tap
- People with NT1 are deficient in orexin.

TOTAL 24-HOUR SLEEP TIME

- The total number of minutes slept in a 24-hour period
- Measured by 24-hour polysomnography, or by actigraphy with a sleep log
- Long sleep time—660 minutes or more—indicates idiopathic hypersomnia.

Where do these criteria come from?

Experts from the US and around the world consider the characteristics that define various sleep disorders, and create guidelines for diagnosing each condition. The most recent version of this document, the International Classification of Sleep Disorders - Third Edition (ICSD-3) was published in 2014.

DIAGNOSTIC CRITERIA

The table below summarizes specific criteria used to differentiate narcolepsy type 1, type 2, and idiopathic hypersomnia.

	NT1	NT2	IH
hypersomnolence /EDS	Yes	Yes	Yes
cataplexy	Yes*	No	No
mean sleep latency (MSL)	⩽ 8 minutes	⩽ 8 minutes	⩽ 8 minutes.
sleep onset REM periods (SOREMPS)	2 or more	2 or more	0 or 1
total 24-hour sleep time[4]	n/a	n/a	⩾ 660 minutes

> In the current diagnostic criteria, idiopathic hypersomnia is differentiated from narcolepsy by the number of sleep onset REM periods. You could have one SOREMP during an MSLT and be diagnosed with IH, but if you have two that would be narcolepsy.
>
> - Dr. Ruoff

*In 2012, researchers showed that some people who have narcolepsy without cataplexy actually are deficient in orexin (Andlauer et. al). If the CSF orexin concentration is below the cutoff value, NT2 diagnosis would change to NT1, even without cataplexy.

MSLT CHALLENGES

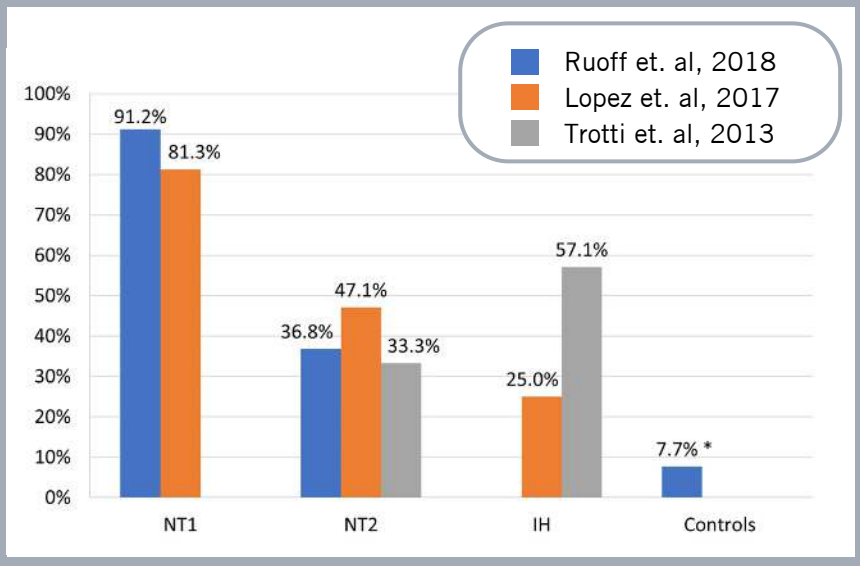
Can the MSLT reliably diagnose narcolepsy type 2 and IH?

The multiple sleep latency test (MSLT) is the primary way sleep specialists test for narcolepsy type 1, type 2, and idiopathic hypersomnia. However recent research has shown that the MSLT doesn't consistently differentiate these conditions.

Dr. Ruoff has been looking into this phenomenon and trying to understand why some people might get one result on their first MSLT and different results on subsequent tests.

In three separate studies, people participated in an overnight polysomnogram and MSLT, and then repeated the overnight test and MSLT six months and one year later. In the graph below, the blue bars show the results of Dr. Ruoff's research (Ruoff et. al, 2018), and the orange and gray bars represent others' research (Lopez et. al, 2017; Trotti et. al, 2013).

Each column represents how frequently people received the same result on subsequent MSLTs for a specific diagnosis: narcolepsy type 1, narcolepsy type 2, and idiopathic hypersomnia. Dr. Ruoff's group also included controls: people who don't have hypersomnolence or other symptoms.



Percent of study participants with consistent MSLT results in repeat tests at 6 months and 1 year.

- In the cluster on the far left, we see that 81-91% people with narcolepsy with cataplexy had consistent MSLT results.
  - About 1 out of 10 people with NT1 did not have consistent results on subsequent MSLTs.
- In the clusters for narcolepsy without cataplexy (NT2) and idiopathic hypersomnia (IH), fewer than half of participants had consistent results on subsequent MSLTs.
- The control group on the far right shows that a small percentage of people have a positive MSLT and no daytime sleepiness or other symptoms. Sleep onset REM periods (SOREMPs) and a low mean sleep latency (MSL) are not entirely specific to central disorders of hypersomnolence.

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MSLT CHALLENGES

False Positives?

Surprisingly, people in the general population — who don't have daytime sleepiness — may meet the diagnostic criteria for narcolepsy. Remember, the current diagnostic criteria for narcolepsy are **falling asleep within 8 minutes** and having **at least two dream periods** (SOREMPs) in the five naps during an MSLT.

- In the general population, an estimated 22% of people fall asleep in less than or equal to 8 minutes (Mignot et al., 2006).
- 6% of men and 1% of women, rested and healthy adults, get a positive result for narcolepsy on the MSLT (Mignot et al., 2006).
    - Having an irregular sleep schedule increases the likelihood of meeting the narcolepsy diagnostic criteria; shift-workers are 30 times more likely to have a positive MSLT (Goldbart et al., 2014).
    - Use of antidepressant medication is a factor in the likelihood of dream periods in naps. Specifically "males with SOREMPs were more likely to take antidepressants than males without SOREMPs" (Mignot et al., 2006).

False negatives?

Many people with idiopathic hypersomnia may not have a mean sleep latency that indicates a central disorder of hypersomnolence.

- In two separate studies, 44% and 39% of people with IH had mean sleep latency over 8 minutes, which means the MSLT would not detect hypersomnia for them (Anderson et al., 2007; Vernet and Arnulf, 2009).
- 71% of people with IH with long sleep had a mean sleep latency over 8 minutes (Vernet and Arnulf, 2009).

Dr. Ruoff explains, "With the addition of a 24-hour sleep study, these patients were able to demonstrate a diagnosis of IH, but if healthcare providers had only done the overnight test and the MSLT, these cases would have been missed." Extended sleep studies are not common in the US, but actigraphy can be used instead to measure total sleep time in a 24-hour period.

> On one hand, in the general population you have 22% meeting the sleep latency criteria for hypersomnia. But in folks with IH with long sleep, many of them are not.
>
> - Dr. Ruoff

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WHAT'S NEXT?

Changes to diagnostic criteria are expected in the next version of the International Classification of Sleep Disorders (ICSD).

Being diagnosed with a chronic illness can significantly affect a person's life and sense of identity. If a diagnosis changes later, it can be confusing and disruptive. It can be reassuring to know that changes in your diagnosis are not caused by something uniquely difficult about you or your sleepiness.

Nosology, the branch of medical science dealing with the classification of diseases, can be compared to **taxonomy**, an often criticized branch of biology which deals with the classification of organisms.

In his book *Letters to a Young Scientist*, E. O. Wilson explains some of the challenges with taxonomy, his field of science: major changes are announced frequently, and that might make it look like the experts are just guessing. But really, new technology has allowed them to better understand the organisms they study and to correct previous inaccuracies. For example, now that we can sequence genes, researchers find that some "closely related" species are actually not from the same evolutionary family. Thus, sometimes a name changes to more accurately represent the organisms in that group.

Similarly, Dr. Ruoff and other sleep researchers believe that the current diagnoses may not accurately categorize people with hypersomnolence based on pathophysiology — the underlying cause of their sleepiness. Changes are expected in the next version of the ICSD, and this is part of the process.

No matter how your sleepiness is labeled, know that it is valid — **your experience is real.** Researchers like Dr. Ruoff are dedicated to better understanding central disorders of hypersomnolence so that people like us can be diagnosed accurately and efficiently.

> “These are already very stigmatized conditions, and then to have your disease name change — it can be a big change in your sense of identity. Don't worry. You're still part of our community. Your symptoms are real.
>
> - Julie

RESOURCES

PATIENT ORGANIZATIONS

Major US Organizations:

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

International Organizations:

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

MORE ABOUT NARCOLEPSY AND IH

- Idiopathic Hypersomnia (IH) Characteristics from Hypersomnia Foundation: https://www.hypersomniafoundation.org/document/ihsummary/
- Narcolepsy Quick Facts from Project Sleep: https://project-sleep.com/wp-content/uploads/2020/08/NARCOLEPSY-QUICK-FACTS-World-Narcolepsy-Day-2020-FINAL.pdf
- Science of Narcolepsy Narcolepsy Nerd Alert episode: https://project-sleep.com/nerd-alert-science-of-narcolepsy/

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APPENDIX

1 What is HLA-DBQ*06:02?

It's a version of the gene that tells your cells how to make Human Leukocyte Antigens (HLA). There are several different versions of the gene, called alleles. Almost every person with narcolepsy type 1 has the allele *06:02 (Mignot, 2001; Tafti et. al, 2014).

2 How common is HLA-DBQ*06:02 in the general population, ie. people without narcolepsy?

The answer varies in different parts of the world where this is studied.

- According to one research group, 12% to 48% of people carry this allele and do not have narcolepsy (Ollila et. al, 2015). This particular study compared groups of white and Chinese participants, and found that there are significant differences across ethnic groups.
- It is estimated that only 1 in 1,000 carriers of HLA-DBQ*06:02 will develop narcolepsy (Basetti et. al, 2019).

3 Is there another way to test for orexin deficiency without a spinal tap?

Dr. Ruoff says, “It would revolutionize evaluation and diagnosis if we had a blood test for orexin/hypocretin. I’m not aware of any developments in this space.”

4 If a person does not get enough sleep during the overnight sleep study, daytime MSLT results would not be valid.

Guidelines say to strive for 7 hours and to hopefully capture at least six hours of sleep in the nocturnal polysomnogram. Daytime sleepiness can only be measured accurately after a night of adequate sleep. So while total sleep time is not part of the diagnosis criteria for narcolepsy, insufficient hours would make the sleep study & MSLT inconclusive.

Sleeping in a new environment can be uncomfortable. We get it. If you're worried about getting enough sleep during your overnight sleep study, communicate with the technician when you get there. They can answer questions about the testing process and might be able to make adjustments to help you feel more comfortable.

GLOSSARY

Actigraphy: a non-invasive technique used to assess cycles of activity and rest over several days to several weeks.

Cataplexy: episodes of muscle weakness usually triggered by strong emotions such as laughter, exhilaration, surprise, or anger. Severity may vary from a slackening of the jaw or buckling of the knees to falling down. Duration may be a few seconds to several minutes and the person remains fully conscious during the episode.

Cerebrospinal fluid (CSF): clear liquid that surrounds the brain and the spinal cord.

Central nervous system (CNS) hypersomnia: a condition characterized by excessive daytime sleepiness. also called **central disorder of hypersomnolence**

Delayed sleep phase disorder: an internal sleep clock (circadian rhythm) disorder that could be mistaken for narcolepsy or IH. It occurs when a person's sleep schedule is delayed by at least two hours, causing them to fall asleep later and wake up later.

Disrupted nighttime sleep: a feature of narcolepsy which includes increased awakenings, arousals, sleep stage transitions, and light NREM sleep (Maski et al., 2020). This might feel like drifting in and out of sleep all night.

Excessive daytime sleepiness (EDS): periods of extreme sleepiness throughout the day that feel comparable to how a person without narcolepsy would feel after staying awake for 48-72 hours. For IH, EDS refers to persistent sleepiness throughout the day that occurs despite adequate or even prolonged nighttime sleep. Also called **excessive daytime somnolence.**

Excessive need for sleep (ENS): the need for an excessive quantity of sleep over a 24 hour period. Increased need for sleep must be associated with deteriorated quality of daytime wakefulness, and cannot be fully resolved by increasing the amount of sleep.

Fatigue: physical and/or mental exhaustion with difficulties in starting or sustaining voluntary activities. Fatigue is not significantly improved by increased rest or sleep.

HLA DBQ*06:02: a gene carried by almost all people with narcolepsy with cataplexy. A positive blood test for this gene strongly supports a diagnosis of narcolepsy type 1.

Hypersomnia: when excessive need for sleep (ENS) has been measured and confirmed by doctors, it is called hypersomnia.

Hypersomnolence: when excessive daytime sleepiness (EDS) has been reported to a doctor, they call it hypersomnolence.

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

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

Idiopathic hypersomnia (IH): a chronic neurological disorder which causes extreme sleepiness during the daytime without cataplexy or REM abnormalities.

Long sleep: at least 660 minutes of sleep in a 24-hour period, measured by actigraphy or an extended sleep study (24-hour polysomnogram). The diagnosis of idiopathic hypersomnia is sometimes split into IH with and without long sleep.

Mean sleep latency (MSL): the average length of time it takes a person to fall asleep over the 4-5 naps during the multiple sleep latency test (MSLT).

Multiple sleep latency test (MSLT): the main test used to differentiate central disorders of hypersomnolence. In a sleep clinic, a person is given 4-5 opportunities to nap every two hours during normal wake times. The specialist uses the test to measure the extent of daytime sleepiness (how fast the patient falls asleep in each nap, also called sleep latency), and also how quickly REM sleep begins.

Narcolepsy type 1 (NT1): a chronic neurological disorder that impairs the body's ability to regulate the sleep-wake cycle, with cataplexy and/or orexin deficiency.

Narcolepsy type 2 (NT2): a chronic neurological disorder that impairs the body's ability to regulate the sleep-wake cycle, without cataplexy.

Orexin (OX): a neurotransmitter involved in the regulation of sleep and wakefulness. Also called **hypocretin.**

Pathophysiology: the structural and functional changes in the body & brain that lead to a disease or symptom.

Polysomnogram (PSG): a comprehensive test used to diagnose sleep disorders. Polysomnography is used to record brain waves, blood oxygen level, heart rate and breathing, as well as eye and leg movements during sleep. When performed overnight, called an **overnight sleep study** or **nocturnal polysomnogram.**

REM sleep: a stage of sleep associated with dreaming and memory consolidation.

Sleep drunkenness: extreme and prolonged difficulty fully awakening, associated with an uncontrollable desire to go back to sleep, which can be accompanied by automatic behavior (performing tasks without conscious self-control and with partial or total loss of memory), disorientation, confusion, irritability, and poor coordination. a severe form of sleep inertia.

Sleep inertia: feelings of grogginess and sleepiness that occur upon awakening, which can result in impaired alertness and may interfere with the ability to perform mental or physical tasks. A form of severe sleep inertia, commonly found in idiopathic hypersomnia, is called sleep drunkenness.

Sleep latency: the length of time that it takes a person to fall asleep.

Sleep log: documents specific sleep and wake habits over a period of time, also called a **sleep diary.**

Sleep onset REM periods (SOREMPs): REM sleep periods that occur within 15 minutes after falling asleep.

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.

Sleep-related hallucinations: visual, auditory, or tactile hallucinations upon falling asleep or waking up. These can be frightening and confusing. See hypnagogic hallucination and hypnopompic hallucination.

Spinal tap: a test used to measure orexin concentration in cerebrospinal fluid. A needle is inserted into the space between two lumbar bones (vertebrae) to remove a sample of cerebrospinal fluid. Also known as a **lumbar puncture.**

Symptomatology: the set of symptoms that characterize a medical condition or are exhibited by a patient.

> Sorry, in the medical community we like to have at least two names for everything.
>
> - Dr. Ruoff

THANK YOU!

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

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

More resources at: www.project-sleep.com

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