



NARCOLEPSY TOOLKIT

A WOMAN'S EMPOWERMENT GUIDE

ABOUT SWHR

The Society for Women's Health Research (SWHR) is a national nonprofit and thought leader dedicated to promoting research on biological sex differences diseases and conditions that disproportionately, differently or exclusively affect women and improving women's health through science, policy, and education. Founded in 1990 by a group of physicians, medical researchers, and health advocates, SWHR is making women's health mainstream by addressing unmet needs and research gaps in women's health. Thanks to SWHR's efforts, women are now routinely included in most major medical research studies and more scientists are considering sex as a variable in their research. Visit www.swhr.org for more information.

SWHR'S NARCOLEPSY PROGRAM

SWHR Science Programs identify research gaps and address unmet needs in diseases and conditions that exclusively affect women or that disproportionately or differently affect women. The Narcolepsy Program was launched in 2022 to address barriers to care in science, education, and policy related to narcolepsy in women. The program engages health care providers, researchers, patients, advocates, and policy leaders to explore strategies to address knowledge gaps, unmet patient needs, and relevant policies that present barriers to equitable and quality care for women with narcolepsy.

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Understanding Sleep and Sleep Disorders

SLEEP ACROSS THE LIFESPAN

The Importance of Sleep

On average, individuals spend 26 years of their lives asleep, 7 years trying to fall asleep, and 33 years in bed. Sleep is an essential function for overall health and well-being and aids in the body's ability to maintain proper brain function and physical health. Poor sleep and sleep disorders are considered a global public health issue, but they are often unrecognized and under-reported and incur high economic burden.

70 million

Americans suffer from chronic sleep disorders¹

80%

of sleep disorders go undetected or undiagnosed²

\$411 billion

is lost in productivity due to sleep disorders each year³

Emerging research points to a relationship between poor sleep and morbidity and mortality. Poor sleep has been linked to 7 of the 15 leading causes of death in the United States, including:

- Cardiovascular disease
- Cancer (malignant neoplasms)
- Cerebrovascular diseases (problems with blood flow and vessels in the brain)
- Accidents
- Diabetes
- Sepsis (bacterial blood poisoning)
- Hypertension

Poor sleep is associated with reduced physical activity, obesity, and increased smoking. Individuals who experience poor sleep are also more likely to report chronic health conditions, mood disorders, and neurodegeneration.

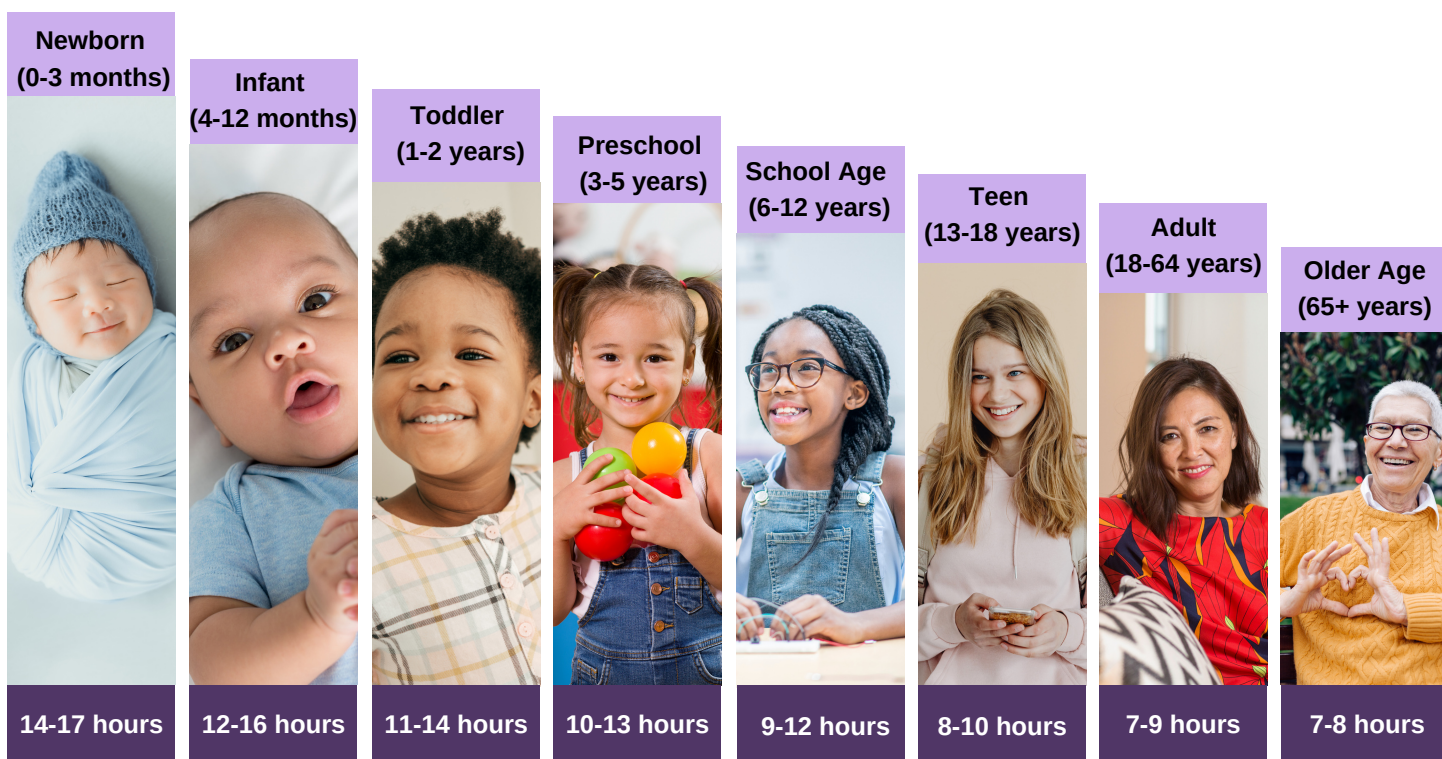
How Much Should You Sleep?

Sleep duration gradually declines over the lifespan—from more than 14 hours for newborns to 9 hours during adolescence, and as few as 7 hours later in life. The recommended amount of sleep that someone should get in a 24-hour period varies across different stages of life.¹



58% of middle school students and 73% of high school students report sleeping less than the recommended 8 hours per night for adolescents.⁴

Recommended Hours of Sleep⁴



While it is recommended that adults get at least 7 consecutive hours of sleep, people are increasingly subjected to shorter and poorer quality sleep due to factors, such as:

- Shift work
- Long work hours
- Daylight savings time adjustments
- Jetlag due to distance travel
- Living in urban and fast-paced environments
- Excessive screen time



15 million individuals in the U.S. work jobs with non-traditional hours. 32% of night shift workers experience excessive daytime sleepiness. Women who work night shifts have a greater risk of developing breast cancer and cardiovascular disease; and are more likely to have irregular menstrual cycles.^{4,5}

Many individuals report getting less than 7 hours of sleep per night⁴

Native Hawaiian/Pacific Islander	46%
African Americans	46%
American Indian/Alaska Native	40%
Asian	38%
Hispanic	35%
White	33%

Understanding Sleep Patterns

There are four stages of sleep – each of which plays an important role in allowing the brain and body the time and opportunity to rest and develop.



REM, on average, makes up **25%** of the sleep cycle⁴

Individuals with a normal sleep pattern will transition through the four stages of sleep 4 to 6 times throughout the night. With each full cycle, the non-REM stages get shorter, and the REM stage gets longer.

*REM = rapid eye movement

SLEEPINESS VS FATIGUE

Although the terms are often used interchangeably, **sleepiness** and **fatigue** are two distinct symptoms – each of which has different health implications and could be indicative of different underlying conditions.

Sleepiness

Sleepiness is the desire to fall asleep. **Excessive daytime sleepiness (EDS)** is characterized by having difficulty staying awake or alert, along with an intense need to sleep during the day. EDS can have a negative impact on relationships, work, cognition, and overall quality of life, and although it is not a disorder, it could be indicative of one. For example, EDS could be indicative of **sleep apnea** or **narcolepsy**.



50% of Americans report feeling sleepy during the day at least 3x per week⁴



Fatigue

Fatigue is extreme exhaustion, a general lack of energy, and weariness. Fatigue can also indicate signs of a sleep disorder, such as insomnia or sleep apnea, or it could be a result of lifestyle habits, certain medications or treatments, or an underlying health condition (e.g., a thyroid disorder, heart disease, or diabetes).

Unfortunately, sleepiness and fatigue have become normalized and can often be dismissed by women as part a regular part of daily life, rather than a sign of a larger health issue. For example, women are more likely to report sleepiness than men, but are less likely to report that their sleepiness affects their relationships or physical activity.

Do not ignore the signs of persistent sleepiness or fatigue. It is important to listen to your body and consult a health care professional when your energy levels are negatively affecting your day-to-day activities. See the **Questions to Ask Your Health Care Provider** in the SWHR Narcolepsy Toolkit for guidance on how to talk to your doctor about your sleep concerns.

SLEEP DISORDERS IN WOMEN



Women generally sleep for longer durations than men, but are more likely to report:

- Higher levels of sleepiness
- Increased use of sleep medications
- Lower quality sleep

1/3 of women get less than the recommended number of hours of sleep⁴

Certain chronic pain conditions that can impact sleep, such as migraine, tension headaches, heartburn, arthritis, and fibromyalgia, also occur more frequently in women than men.

Sleep disorders disproportionally and differently affect women, in part, due to natural biological processes, such as menstruation, pregnancy, and menopause.

Menstruation

Women who experience premenstrual syndrome (PMS) are 2x more likely to report insomnia-like symptoms. Up to 1/3 of women experience cramps, headaches, and bloating that disrupt their sleep during their menstrual cycle.⁴

Pregnancy and Postpartum

Sleep problems, such as restless legs syndrome and obstructive **sleep apnea**, are common during pregnancy, and especially during the third trimester. During the postpartum period, women can experience sleep disruptions due to the sudden decline in hormones and the unpredictable sleep patterns that come with caring for a newborn.

Menopause

During menopause, hot flashes and night sweats can make a good night's sleep nearly impossible for some women. In other cases, trouble sleeping could be the result of underlying conditions that developed during the perimenopausal years, such as insomnia, restless legs syndrome, and obstructive sleep apnea.



Sleep Disorders to Consider

Insomnia is a sleep disorder that makes it difficult to fall asleep or stay asleep. Insomnia is the most common sleep disorder in the United States – 1 in 3 adults experience periodic insomnia, and 30 million adults suffer from chronic insomnia. Women, and especially menopausal women who experience disruptive vasomotor symptoms, are up to 40% more likely to have insomnia.^{4,7}

Sleep Apnea is a disorder in which breathing repeatedly starts and stops during sleep, often due to an obstruction that causes the airway to be partly or completely collapsed during sleep. Twenty-five million adults in the United States have a form of sleep apnea. While men are more likely to have sleep apnea, cases increase significantly for women after age 50.^{4,9}

Restless Legs Syndrome, also known as Willis Ekbohm disease, is an uncomfortable sensation (i.e., itching, prickling) that creates an irresistible urge to move the legs after extended periods of inactivity, such as sitting or sleeping. Restless legs syndrome affects 5-10% of adults, and women are 2 times more likely to have this sleep disorder, with pregnant women and women with multiple children at even higher risk.⁴

Obstructive sleep apnea is under-reported and under-diagnosed in women because of gender differences in symptom presentation. While men commonly report snoring and gasping, women report fatigue and depression.⁸



Circadian rhythm sleep disorders occur when the body's internal clock is out of sync with the 24-hour light-dark cycle. These sleep-wake cycle disorders can be caused by different factors, such as jet lag, shift work, or melatonin levels, resulting in difficulty falling and staying asleep, waking up, and overall poor-quality sleep. 10% of adults and 16% of adolescents experience circadian rhythm sleep disorders, with an increased likelihood to occur in women.⁶



Narcolepsy is a chronic sleep disorder that is characterized by persistent and **excessive daytime sleepiness**, an inability to regulate sleep-wake cycles, and in some cases, **cataplexy** (sudden change of muscle tone, which can be triggered by strong emotions). Although narcolepsy affects men and women equally and similarly, women are diagnosed an average of 12 years later than men after symptom onset.^{10,11}

Idiopathic hypersomnia (IH) is a neurological sleep disorder that results in excessive daytime sleepiness, despite sleeping longer than normal hours (i.e., 10+ hours per day). IH affects 20-50 per 1 million individuals, both men and women alike. Those with IH experience trouble waking up and a prolonged feeling of grogginess, even after a long sleep or nap.¹²

For more information about sleep disorders that affect women, see SWHR's **Women and Sleep: A Guide for Better Health.**

Understanding Narcolepsy

WHAT IS NARCOLEPSY?



Narcolepsy is a chronic neurological disorder that affects the brain's ability to regulate sleep-wake cycles. It results in persistent and **excessive daytime sleepiness (EDS)** and in many cases, **cataplexy**. Individuals with narcolepsy may also experience disturbed nighttime sleep, sleep-related hallucinations, temporary sleep paralysis, memory issues, and difficulties concentrating. The exact cause of narcolepsy is unknown.

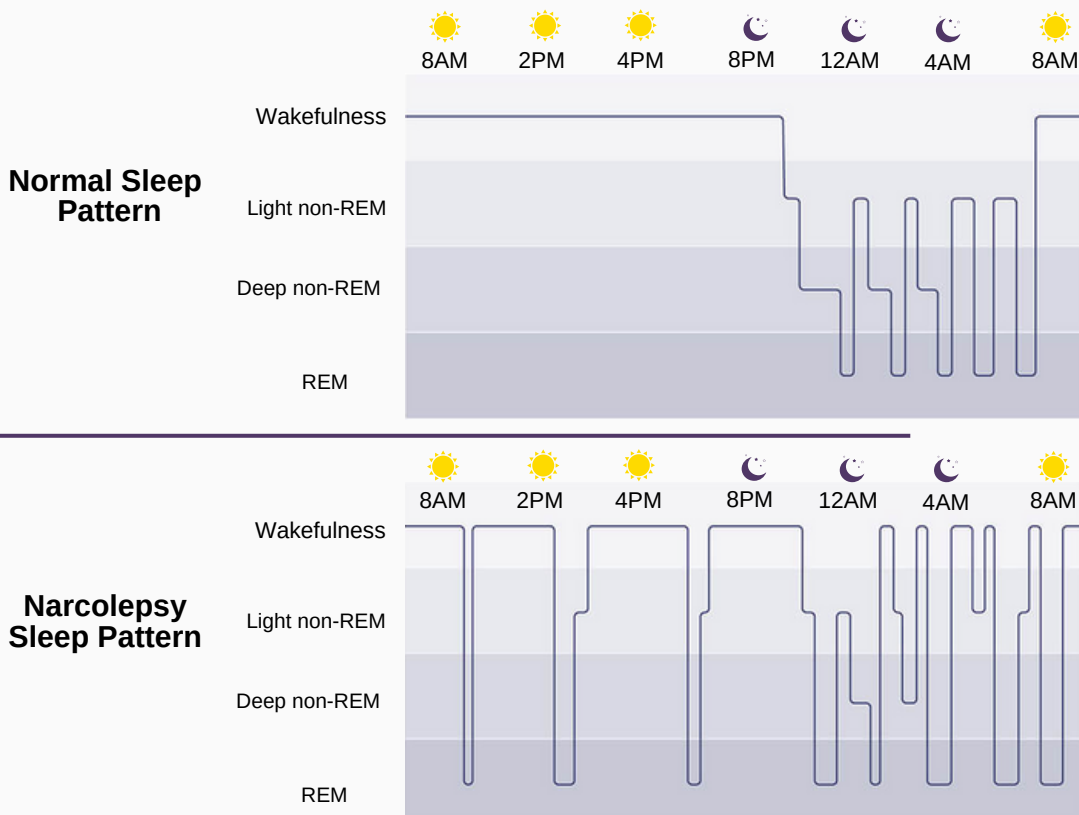
Cataplexy is sudden change in muscle tone in one or more parts of the body that can be triggered by strong emotions (e.g., fear, anger, stress, joy, laughter), resulting in weakness or involuntary movements.

130,000 to 200,000 individuals in the U.S. have narcolepsy¹⁰

The severity, duration, and frequency of cataplexy attacks vary from person to person. While they typically result in a loss of muscle tone, pediatric patients and individuals with newly developed disease might experience an activation of muscle movements or attacks that occur independent of emotions.

Narcolepsy Sleep Patterns

With a normal sleep pattern, it takes 60-90 minutes to transition from the non-REM stages to the REM stage, providing sufficient opportunity for restorative sleep (stage 3), which promotes immunity, cognition, and memory. A person with **narcolepsy**, however, transitions rapidly from non-REM to REM stages, blocking the ability to achieve "rest" even after a full night's sleep.



Types of Narcolepsy

There are two types of narcolepsy. **Narcolepsy Type 1 (NT1)** occurs with excessive daytime sleepiness and cataplexy, whereas **Narcolepsy Type 2 (NT2)** occurs without cataplexy.

NT1 is **2-3x** more common than NT2¹⁰

While the exact cause of narcolepsy is unknown, NT1 is thought to result from a combination of genetic, autoimmune, and environmental factors. Individuals with NT1 show a loss of up to 90% of the neurons (brain cells) that produce a protein called **hypocretin**, though it is unclear what triggers the immune system to attack these neurons. Individuals with NT2 tend to have normal levels of **hypocretin**.

NT1 can be diagnosed in individuals who do not have cataplexy but present with low levels of hypocretin. Hypocretin, also known as orexin, is a protein produced in the brain that helps regulate sleep-wake cycles.



RISK FACTORS AND COMMON SYMPTOMS

Narcolepsy symptoms often begin to show up during adolescence, but can go unrecognized for many years before a diagnosis is made. On average, women are diagnosed with narcolepsy 28 years after symptom onset – 12 years longer than it takes for men to be diagnosed.¹¹

Risk factors for narcolepsy include:

- Age (10-20 years old)
- Family history
- Immune or environmental triggers
- Brain trauma or infection



Family history increases the risk of developing Narcolepsy Type 1 by 1-2%, however, people can develop narcolepsy without a family history.¹⁰



Secondary narcolepsy is a form of narcolepsy that occurs after injury to the hypothalamus in the brain, as a result of brain trauma or infection.

Common symptoms of narcolepsy include:

- **Excessive daytime sleepiness (EDS)**
- Sudden attacks of sleep
- **Sleep paralysis**
- Changes in rapid eye movement (REM) sleep
- Hallucinations
- Disturbed nighttime sleep or insomnia
- **Cataplexy** (in NT1)

Symptoms of narcolepsy present similarly in adults and adolescents; however, EDS is often mischaracterized in teens as a behavioral problem, such as restlessness or irritability. Some symptoms are also commonly mistaken for other conditions, such as depression or idiopathic hypersomnia, leading to an incorrect or delayed in diagnosis. In women, especially, narcolepsy is frequently misdiagnosed as a psychiatric condition.^{11,13}

CONDITIONS COMMONLY ASSOCIATED WITH NARCOLEPSY



Individuals with narcolepsy often tend to have other health conditions, such as:

- Sleep disorders (e.g., sleep apnea, insomnia)
- Mental health disorders (e.g., mood disorders, depression, anxiety)
- Cardiovascular disease
- Metabolic disorders (e.g., diabetes)
- Neurologic disorders (e.g., epilepsy, Alzheimer's disease)

57% of individuals with narcolepsy experience depression related to narcolepsy¹⁴

Narcolepsy is associated with increased risk of serious accidents and injuries, and over time, narcolepsy may also impact relationships, work, cognition, and overall quality of life. Women who are diagnosed with narcolepsy also have higher associations with mental health and metabolic disorders, and other chronic conditions over the long term.

If you have been diagnosed with narcolepsy, talk to your health care provider about a personalized plan for your care. For more information, see the **Managing Your Narcolepsy Care** section of the SWHR Narcolepsy Toolkit.

Managing Your Narcolepsy Care

DIAGNOSING NARCOLEPSY

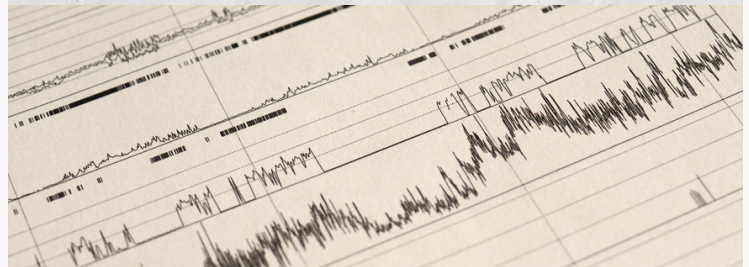


Diagnosing **narcolepsy** is a multi-layered process that engages multiple health care professionals. Narcolepsy symptoms are often mistaken for mood disorders, behavioral issues, and other conditions, such as insomnia, attention deficit hyperactivity disorder (ADHD), depression, or anxiety, which results in significant delays in diagnosis.

Even though men and women experience similar symptoms, women are, on average, diagnosed 28 years after symptom onset – 12 years longer than men.¹¹

A narcolepsy diagnosis can sometimes be made based solely on the presence of **EDS** and **cataplexy**; however, it often requires diagnostic tests to further evaluate sleep and rule out other conditions. Sometimes, a lumbar puncture (also known as a spinal tap) can be used to help measure the levels of **hypocretin** in the fluid surrounding the brain and spinal cord. Low levels of hypocretin can indicate that a person has NT1.

Cataplexy is a symptom almost exclusive to narcolepsy, and is present in up to 75% of individuals with narcolepsy.¹⁵



Sleep Studies

In addition to a physical exam and sleep history evaluation, you might be referred for a sleep study. The sleep studies typically used to diagnose narcolepsy are the **polysomnogram (PSG)** sleep study and the **multiple sleep latency test (MSLT)**.

Polysomnogram (PSG) sleep study

An overnight recording of the brain, muscle activity, breathing, and eye movement to determine when REM occurs.

Multiple sleep latency test (MSLT)

A test generally taken the day following a PSG to assess EDS, which is done by determining how quickly someone falls asleep and when REM occurs. During the test, an individual takes 5 short naps with 2 hour breaks in between over the course of a day. A urine toxicology screen may also be obtained during the study.

Preparing for a Sleep Study

Sleeping as comfortably and naturally as you would at home is important for obtaining accurate results. Sleep studies are generally conducted overnight at a specialized sleep center or hospital that has the proper testing equipment and technicians to evaluate your sleep.

It helps to have a detailed record of your sleep habits (e.g., bedtime, wake time, levels of sleepiness throughout the day) so that you can share a more complete picture of your experience with the sleep specialists. A **Weekly Narcolepsy Diary** is provided in the SWHR Narcolepsy Toolkit to help you track your sleep, symptoms, treatments, and other relevant details.



During the study, you will be connected to computers that will monitor your brain and muscle activity, breathing, and eye movement. A camera may also be used to record your movements and sleep positions throughout the night.

Do not hesitate to ask your provider questions beforehand to help you feel more comfortable and prepared for your sleep study. See the **Questions to Ask Your Health Care Provider** section of the SWHR Narcolepsy Toolkit for a list of sample questions to ask your referring provider or sleep study technician.



Prior to your sleep study, you may be asked to temporarily discontinue certain medications (e.g., antidepressants or cannabinoids) that may affect the results of the sleep study. Make sure to talk to your primary care provider before you stop or restart taking any such prescription medications.

Preparing for your sleep study:

- Keep a detailed record of your sleep and sleep habits in a sleep diary
- Follow your regular daytime routine in the days leading up to the study
- Avoid naps during the day of the sleep study
- Avoid caffeine, alcohol, and sedatives during the day of the sleep study
- Avoid hair products that may interfere with testing equipment (e.g., hair spray, oils, gels)
- Review current medications with your sleep specialist

Some personal items to bring to the sleep study might include:

- Comfortable clothes to sleep in
- A pillow and blanket
- Oral hygiene products (e.g., toothbrush, toothpaste, floss)
- Skin care regimen products
- Reading material (try to avoid electronic devices)

TREATMENTS FOR NARCOLEPSY

While there is no cure for narcolepsy, with proper treatment, symptoms can be stabilized and even improve over time. Some treatment options address cataplexy, while others are used to reduce **excessive daytime sleepiness (EDS)** and other associated symptoms. Finding the right combination of medical and behavioral therapies can help to manage symptoms and enhance overall quality of life. As with any treatment, discuss risks, benefits, and potential side effects with your health care provider to determine the best option for you.

Medical Therapies

- **Wake-promoting medications** are usually the first line treatment to reduce EDS, as they generally have fewer side effects and reduced or no risk of addiction. These types of medications typically target dopamine neurotransmission or histamine activity in the brain, and can also be effective in treating cataplexy.
- **Stimulants** are also effective in alleviating EDS; however, these medications have increased risk of addiction and can have adverse side effects, such as irritability, nervousness, shakiness, heart arrhythmia, and sleep disruption.
- **Central nervous system depressants**, typically in the form of oxybate salts, are used to treat cataplexy and EDS. They may be used alone or in combination with wake-promoting medications.
- **Antidepressants** can be effective in controlling cataplexy, hallucinations, and sleep paralysis. Selective serotonin and noradrenergic reuptake inhibitors (SSRIs/SNRIs) generally have fewer side effects than tricyclic antidepressants (TCAs), though both can cause male impotence, high blood pressure, and heart arrhythmia.

Lifestyle Approaches

- Short naps (15 to 20 minutes) scheduled throughout the day
- A consistent sleep schedule (going to sleep and waking up at the same time each day, even on the weekends)
- Reduced screen time before bed
- No caffeine, alcohol, or large meals before bed
- No nicotine or smoking
- Daily exercise
- Relaxation before bed and overall stress reduction



DECIDING ON A TREATMENT PLAN

Things to consider when creating your narcolepsy care plan:

- Your age
- Lifestyle and activity levels
- Symptom management
- Family planning goals
- Treatment efficacy and side effects
- Other health risk factors and conditions
- Health insurance coverage

Treatment of narcolepsy is similar in adults and adolescents. However, additional precautions should be taken when selecting medications and doses for children and teens. For example, a cardiovascular evaluation is recommended before prescribing stimulants for an adolescent.

Treatment should take into account your short- and long-term health and life goals. As you decide on a treatment plan with your provider, you may choose to incorporate a combination of approaches. These may change over time. Discuss with your provider(s) which treatment(s) will address your symptoms and which will address other related health conditions as well as your personal needs and goals for treatment now and in the future.

It is also important to find out the details of your health insurance coverage for the treatment you desire to pursue.

Ask your provider to outline what a follow-up plan for monitoring your health looks like, including referrals to additional providers and how often to schedule follow-up visits.

Questions to Ask Your Health Care Provider

Compiling a list of questions before visiting your provider may help you feel more prepared to discuss your experience with narcolepsy and plans for symptom management. Questions may vary depending on the type of narcolepsy, severity of symptoms, and where you are in your diagnosis and treatment journey.

Sleep Study Questions:

- How should I prepare for my sleep study?
- What will happen on the day of my sleep study? How long will the study last?
- Can I drive myself to the sleep study? Should I have someone come and wait for me during the test?
- What happens if I can't fall asleep during the sleep study?
- Can I take a bathroom break during the study?
- How long will it take to get the results from the sleep study?
- Will the sleep study be covered by insurance?

General Diagnosis and Care Management

- I am experiencing *[EDS/cataplexy/hallucinations/sleep paralysis]*. What can I do to manage these symptoms?
- Are the symptoms I am experiencing a result of narcolepsy or a different condition?
- How can narcolepsy affect my long-term health?
- How can narcolepsy affect my lifestyle?
- What are the risks and benefits of the different medication options available to me?
- Which medications are covered by my insurance?
- Which medication(s) do you recommend I try first, and why?
- What natural or lifestyle approaches would you suggest to help manage my symptoms?
- What risks does narcolepsy pose to pregnancy, childbirth, and breastfeeding?
- Can you recommend some resources that can help me talk to my partner, family, friends, and employer about my narcolepsy?
- Are there additional resources I should explore or support groups you recommend?

It is helpful to keep an accurate record or journal of your treatments and how each affects your symptoms and health. A **Weekly Narcolepsy Journal** is available in the SWHR Narcolepsy Toolkit for you to fill out and take with you as a reference during your conversations with your provider, so you can discuss any necessary modifications to your plan.

Narcolepsy Care Team

Many women start their narcolepsy journey with their primary care provider; however, your narcolepsy care might benefit from additional health care professionals with subspecialty expertise, such as a:



Neurologist



Sleep Specialist



Mental health professional



Cardiologist



Dietician or nutritionist



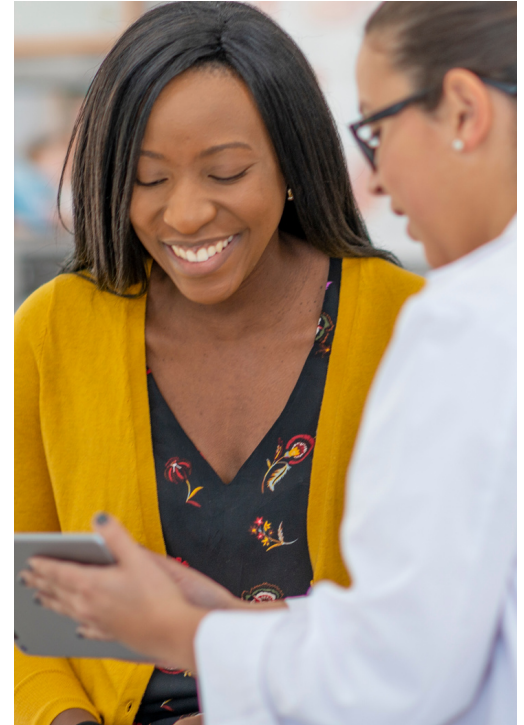
Ear, nose, and throat (ENT) provider



Endocrinologist



Pulmonologist



Shared Decision-Making

Patient-centered health care often involves providers and patients working together to make decisions about tests and treatments throughout their health care journey. You should feel comfortable and empowered to ask as many questions as needed to be confident in your health care provider and in your narcolepsy care plan. Talk to your provider early and often about any concerns you may have. If you think your provider or treatment plan is not working well for you, do not be afraid to consult another provider.



What does shared decision-making look like?

- Understanding the available treatment options and their risks and benefits
- Evaluating your options, based on your short and long-term goals and individual values
- Empowerment to communicate openly with your provider
- Feeling prepared to make informed decisions about your care, in collaboration with your provider
- Giving your **informed consent** before moving forward with any kind of procedure or treatment

Informed consent is a process of communication and education to get patient permission for care, treatment, or services. Consent is typically given by signing forms that explain key medical and legal implications of the care services to be rendered.

NAVIGATING HEALTH INSURANCE

It is important that you speak with your health care providers and insurance company to check what is covered by your insurance plan and reduce high out-of-pocket costs. Here are some tips on how to effectively engage with your insurance company.

Know the details of your insurance policies. Request a copy of your policies that explain:

- Policy expiration date
- Premium payment amounts
- In-network and out-of-network benefits
- Services covered (e.g., screenings, tests, medications, therapies, medical appointments)
- Prior authorization processes to receive services or medications
- Referral processes to see various health care professionals

Individuals with narcolepsy incur **2x** higher health care costs than average¹⁶



Understand the financial aspects of your policy. Insurance plans rarely cover 100% of health care costs, requiring patients to pay some portion of the costs out-of-pocket. There are three primary out-of-pocket costs:

- **Deductible** – a preset amount you must pay annually before your insurance coverage fully kicks in
- **Coinurance** – an amount (often a percentage) you must continue to pay for services after the deductible has been reached
- **Copayment** – a preset, flat fee you must pay at each doctor's visits and for prescriptions, tests, etc.; these payments do not count towards your annual deductible

Step therapy (also known as "fail first") is a policy implemented by an insurance company that requires a patient to try and "fail" a lower-cost treatment before a clinician can prescribe newer or more expensive treatment option. This policy often delays preferred treatments and can result in unnecessary disease progression.

Be aware of special coverage requirements. Some insurance companies have **prior authorization** requirements that must be met before they will cover a specific medication, treatment, or procedure. Sometimes, an insurance company may require that certain medications are tried and 'failed' before allowing the patient access to their clinician's preferred treatment method. This is called **step therapy**. Talk with your health care provider to determine if a required treatment is subject to step therapy, as a delay in treatment may result in further progression of your condition or affect your long-term health.

In most cases, your doctor's office will be responsible for submitting the prior authorization. Work with the office staff to ensure the necessary forms are completed accurately and submitted quickly. For additional help navigating the process, you can request the support of a case manager at your insurance company. This is typically a free resource provided by the insurance company. You may also find help through patient advocate or patient navigator programs and support organizations. See the **Support Groups and Organizations** section of the SWHR Narcolepsy Toolkit for additional information.

Filing Claims & Appeals

If your insurance company denies the claim for your narcolepsy care, you have the right to appeal the decision.

Insurers are required to tell you how you can dispute their decisions and have them reviewed by a third party. **If you decide to appeal, it is important to take action immediately.** Carefully review your insurance policy to understand what it covers and outline your argument for why your insurer should honor your appeal.

Your insurance company must notify you why your claim was denied in writing and within specified timeframes, based on the circumstance. Typically, these timeframes are:

- **15 days** for prior authorization of a treatment
- **30 days** for medical services already received
- **72 hours** for urgent care cases

Additional Resources

- **Employer** – If you receive health insurance coverage through your employer, contact the human resources department. They may have dedicated case managers who can assist with your appeal or connect you with potential state-run external review processes.
- **State** – Many states offer administrative help with difficult claims. If you need help filing an internal appeal or external review, contact your state's [Consumer Assistance Program](#). States also offer free health benefits counseling services for Medicare beneficiaries and their families or caregivers, such as [State Health Insurance Assistance Program \(SHIP\)](#).
- **Federal** – Contact the U.S. Department of Labor [Employee Benefits Security Administration](#) for more information about employer-sponsored benefits.



Patient assistance programs (PAPs) can help individuals who are underinsured or have no health insurance cover the costs of some medications. Your health care provider or insurance company may have more information about these programs offered by pharmaceutical companies, nonprofit organizations, and government agencies.

ADJUSTING TO LIFE WITH NARCOLEPSY

Even well-managed narcolepsy can present significant challenges to daily living. Because narcolepsy is so rare, people may not understand the diagnosis. They may have certain misconceptions about narcolepsy, given how it is depicted in the media. Educating your friends, loved ones, and employers about the realities of living with narcolepsy can help reduce stigma and help them to better understand your condition and support you throughout your journey.



Studies have suggested that symptoms of narcolepsy can positively influence a person's creative performance and achievement.¹⁷

Individuals report that their cataplexy attacks occur less frequently after age 65.¹⁸

While narcolepsy is a life-long disorder that has no cure, **studies show that narcolepsy does not get worse with age, and many individuals report that their symptoms stabilize and can even improve with proper management.**

Steps you can take to help adjust to your diagnosis:

- Learn your triggers
- Educate friends and family
- Talk with others about your experience (positives and challenges)
- Be flexible and forgiving of yourself; try not to compare your journey to others
- Stick to your treatment regimen
- Seek support
- Learn as much as possible about your specific diagnosis and overall health
- Know your rights and advocate for yourself
- Consider participating in clinical trials

Inclusion of women across all stages of life, including adolescents, pregnant and lactating populations, and menopausal women, in clinical trials is important for developing treatment options that improve outcomes for women.

For more information, see the **Narcolepsy Education and Support Group** section of the SWHR Narcolepsy Toolkit.

Wellness Tips for Narcolepsy Across the Lifespan

LIVING WELL WITH NARCOLEPSY

Emotional Wellbeing

Managing narcolepsy and its symptoms can be very challenging, and sometimes, overwhelming. Both men and women with narcolepsy experience higher rates of depression and anxiety.

57% of women with narcolepsy experience depression¹⁴
32% of women with narcolepsy experience anxiety¹¹

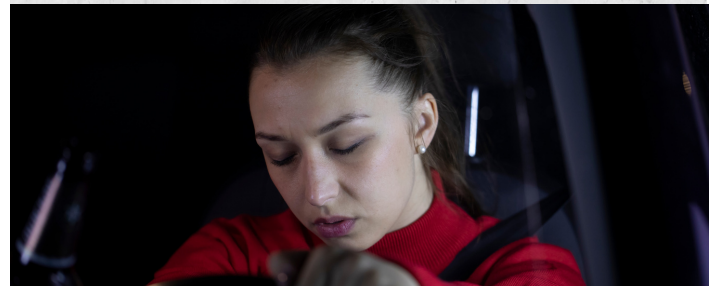
Schedule time with your health care provider to discuss any concerns or challenges you are experiencing. Together, you can create a plan to support your mental health and wellness. Seeking counseling, therapy, and online support can make a big difference in the quality of your life.

- 1 Seek care and support.** Connecting with other people who have narcolepsy can help support you along your journey and introduce you to others who may have similar experiences.
- 2 Share your experience.** Consider talking about your narcolepsy symptoms and how they affect your day-to-day life. While it is important to share your challenges, it is also helpful to discuss your goals and successes with trusted family, friends, and coworkers. Many people are not familiar with narcolepsy, so educating them can spread awareness and create support.
- 3 Communicate openly.** Sharing openly about your experience with friends, loved ones, and your medical team gives them the opportunity to understand your journey with narcolepsy.
- 4 Ask for help.** Your support network wants to help you but may need to be told exactly what you need and when. Tell them how they can help during a cataplexy or sleep attack or express how they can support you in general.

Safety Tips for Driving

Narcolepsy can lead to safety issues and increased risk of accidents. It is important to gauge what activities tend to make you sleepy and when to avoid them. Car accidents can be common among people with narcolepsy, especially during long road trips or while driving on the highway. Consult with your health care provider to determine whether your symptoms are well-managed and stable enough for you to drive safely.

Up to 30-50% of individuals with narcolepsy have reported accidents or near accidents that involved falling asleep while cooking, smoking, running machinery, and crossing the street.¹⁹



Individuals with narcolepsy are **3-4x** more likely to be in a car accident¹⁹

If you do get behind the wheel:

- Take short breaks and schedule naps during long trips
- Take turns driving with someone else
- Avoid driving at night or after a big meal
- Consider alternative transportation options (public transportation, taxis, or ride shares)

NARCOLEPSY AND STUDENT LIFE

Adults and adolescents experience symptoms of narcolepsy similarly; however, if undiagnosed, **excessive daytime sleepiness (EDS)** can be mistaken as restlessness, irritability, or misbehavior among children and teens.

80% of adolescents with narcolepsy have cataplexy¹⁰

Adolescents with narcolepsy type 1 (NT1) often show a more subtle version of **cataplexy** – mild weakness, half-closed eyes, slight tongue protrusion, and a wobbly walk. They are also more likely to be overweight and start puberty early (before 8 or 9 years old).



School Accommodations

Due to the effects of EDS and cataplexy, adolescents may experience challenges with school, such as frequent tardiness, falling asleep in class or while studying, forgetfulness, and brain fog. Still, with proper treatment, a consistent routine, and adequate support, adolescents can be very successful in their educational pursuits.

Under the Americans with Disabilities Act (ADA) and the Individuals with Disabilities Education Act (IDEA), K-12 public schools are required to create special accommodations for students with a disability. Narcolepsy is an eligible condition for this accommodation, allowing students to participate in specialized education plans, such as a [504 Plan](#) and/or an [Individualized Education Plan \(IEP\)](#).

Qualifying for narcolepsy accommodations will likely involve having the student with narcolepsy undergo an evaluation and provide a note from their health care provider(s). Once qualified, the student and their parents must collaborate with their providers and the school faculty and staff (administrators, teachers, and nurse) to determine which accommodations should be put in place to best help the student succeed in their school environment.

**Remember, every student is different.
Figuring out what works best for you will
depend on your individual symptoms,
needs, and goals for school.**



Example accommodations for school and learning might include:

- Help with note-taking, shared notes, or recordings of class to review again later
- Audio versions of textbooks
- Flexible scheduling of classes and tests (e.g., when student is most alert)
- Flexible deadlines for assignments
- Extra time or short breaks during tests
- Separate and comfortable (e.g., natural light, air conditioned) testing room

Students with narcolepsy graduate from college at similar rates to those without.¹⁹

Many colleges and universities offer support to students with disabilities, typically through a student support services or resource center. When transitioning into higher education, find out what services your potential school has. Additional accommodations to promote your success at college might include:

- Priority scheduling of classes
- Alternative course formats (e.g., online, asynchronous, practicum)
- Independent dorm room



Helpful Tips for Teens with Narcolepsy

- Take a brief nap after school, but not too close to bedtime
- Prioritize your sleep, even if that means limiting after-school activities
- Keep your bedroom comfortable (e.g., quiet, dark, and cool)
- Limit the use of electronics late at night and in the bedroom
- Communicate openly and regularly with teachers, classmates, and school administration
- Create a daily bedtime routine
- Prioritize exercise and a healthy diet
- Do not overuse caffeine and avoid energy drinks

WOMEN WITH NARCOLEPSY IN THE WORKPLACE



Narcolepsy can present certain challenges and safety concerns in the workplace, especially for jobs that require operating heavy machinery or driving long distances. Women who fear losing their job or who prefer to keep their condition private might have difficulty disclosing their narcolepsy diagnosis to an employer. If you decide that you would like to tell your employer about your narcolepsy or another medical condition, the following tips can provide some guidance.

Workplace Accommodations

Under the Americans with Disabilities Act (ADA), employers are required by law to provide reasonable accommodations in the work setting for those who are eligible and have received approval. Your employer is responsible for creating and maintaining a safe and healthy work environment for all employees, including those with disabilities.

Before meeting with your supervisor or human resources department, consider preparing a list of your symptoms, how they affect your ability to function at work, and treatments or actions you are taking to address them, especially as it relates to your job. You may also want to ask your health care provider for a letter describing your symptoms to help your employer better understand how they can support you. Conversations might feel uncomfortable at first, but do not be afraid to advocate for the support you need to be safe and successful in your job.

Individuals with narcolepsy take **2.5x** as many short-term disability days²⁰

Examples of workplace accommodations include:

- Flexible work hours
- A designated nap space
- Scheduled nap breaks
- A wake-promoting workspace (e.g., a standing desk with natural light)
- Working from home, if possible

Helpful Work-Life Balance Tips for Narcolepsy

- Optimize your workspace (e.g., get a standing desk, stay cool)
- Stay active while working (e.g., chew gum, stand, walk around, or stretch)
- Schedule tasks throughout the day according to your alertness (e.g., break up mundane tasks across your day)
- Take a brief nap after work, but not too close to bed time
- Maintain a consistent sleep schedule, even on the weekends
- Limit the use of electronic devices right before naps or late at night
- Consider getting an occupational therapist evaluation for more personalized recommendations

NARCOLEPSY AND MOTHERHOOD

Planning for a Family

Many women worry about whether they will pass narcolepsy onto their children. While there is a genetic component to narcolepsy, most people develop narcolepsy without any family history. If this is a concern, consider talking to your health care provider.

10% of individuals with NT1 have a close relative with similar symptoms²¹

Treatment Modifications During Pregnancy

Treatment of narcolepsy during pregnancy is a multi-layered process that engages multiple health care professionals. It might be helpful to connect your provider for your pregnancy (e.g., obstetrician/gynecologist) with your other health care providers (e.g., neurologist) to coordinate care while pregnant. For high-risk pregnancies, you might be referred to a maternal-fetal medicine specialist for additional expertise.



1/3 of women report worse symptoms during pregnancy²²



Studies have not provided conclusive data about medications' impact on developing and newborn babies, so there are no clinical guidelines available. Many health care providers will suggest that women trying to conceive or who are pregnant or breastfeeding reduce or stop medications for narcolepsy, especially stimulants.

This deferment could result in a woman with narcolepsy going without treatment for years at a time to pursue childbearing. It is possible to manage narcolepsy in ways other than with medication. However, it is important to balance and monitor the potential health risks and benefits for both mother and baby throughout the pregnancy.

Cataplexy and Childbirth

Women with cataplexy are at higher risk for gestational diabetes, anemia, and weight gain during pregnancy; however, these conditions can be well-managed and do not generally lead to further complications during pregnancy. While cataplexy can be triggered by strong emotions, attacks during labor are rare.²³

Narcolepsy itself does not increase the risk for adverse birth outcomes, and most women deliver vaginally without any complications.^{22,23}



Care and Safety After Birth

New mothers may experience changes in symptoms, particularly due to unpredictable sleep patterns and stressors that come with caring for a newborn. Additional support from your family and friends is extremely important during the postpartum period. It is also important to regularly check in with your provider to adjust your narcolepsy care plan as needed to best manage your symptoms and ensure that you and your newborn are safe and healthy.

There are no formal guidelines concerning breastfeeding while taking narcolepsy medications; the research data is very limited. It is important to remember that different providers will have different recommendations and your decision should be made by weighing your own personal preferences, symptom severity, and overall experience with narcolepsy.



NARCOLEPSY AND THE MENOPAUSE TRANSITION



As a woman gets older, her ovaries produce less of the hormone estrogen and her menstrual cycle begins to change and eventually stops, resulting in menopause.

During the menopause transition, or perimenopause, this decline in estrogen affects the body's ability to regulate its temperature. Many women experience vasomotor symptoms, such as hot flashes, night sweats, and sleep disturbances. Trouble sleeping can also result from other underlying conditions that commonly develop during perimenopause, such as insomnia, restless legs syndrome, and obstructive sleep apnea. These disruptions can be especially challenging for women living with narcolepsy. Therefore, prioritizing sleep is extremely important in managing your narcolepsy during menopause.

In addition to managing your narcolepsy symptoms and maintaining good sleep hygiene, below are some approaches to address hot flashes:

- Staying cool with light, layered clothing and bedding
- Cooling devices (e.g., handheld and wearable devices, cooling gel bed toppers)
- Cognitive behavioral therapy and mindfulness strategies
- Hormone therapy
- Other medications that may help manage hot flashes (e.g., low-dose antidepressants, anticonvulsants, hypertension drugs, bladder relaxants)

Tips for Good Sleep Hygiene

- **Maintain a consistent sleep schedule, even on the weekends**
- **Limit the use of electronic devices right before naps or late at night**
- **Keep your bedroom comfortable (e.g., quiet, dark, and cool)**
- **Avoid large meals, caffeine, and alcohol before bed**
- **Exercise daily**

To learn more about menopause and managing vasomotor and other symptoms, see the [**SWHR Menopause Preparedness Toolkit**](#).

Resources for Women Living with Narcolepsy

GLOSSARY

Cataplexy – A sudden change in muscle tone (loss or activation) that is often triggered by strong emotions (e.g, fear, anger, stress, joy, laughter), resulting in involuntary movements in one or more parts of the body

Excessive daytime sleepiness (EDS) – Difficulty staying awake or alert with an intense need to sleep during the day

Fatigue – A general lack of energy or weariness, but with the ability to remain awake

Hypocretin – A chemical produced by neurons in the hypothalamus that aids in the control of sleep and wakefulness; also known as orexin

Idiopathic hypersomnia (IH) – A neurological condition that results in excessive daytime sleepiness, despite longer than normal sleep duration (i.e., 10+ hours per 24-hour period)

Multiple sleep latency test (MSLT) – A diagnostic test that helps to assess excessive daytime sleepiness (EDS) by determining how quickly someone falls asleep, and when REM occurs

Narcolepsy – A neurological sleep disorder that results in excessive daytime sleepiness (EDS) and the inability to regulate sleep-wake cycles, with or without cataplexy (type 1 and type 2, respectively)

Orexin – A chemical produced by neurons in the hypothalamus that aids in the control of sleep and wakefulness; also known as hypocretin

Polysomnogram (PSG) – An overnight sleep study that records brain and muscle activity, breathing, and eye movement to determine when REM sleep occurs

Prior authorization – A process used by some health insurance companies that requires the review and approval of a specific procedure, service, or drug before it is prescribed

Secondary narcolepsy – A type of narcolepsy that occurs after injury to the hypothalamus, as a result of brain trauma or infection

Sleep apnea – Abnormal breathing during sleep. There are three types of sleep apnea: obstructive sleep apnea (OSA), central sleep apnea (CSA), and mixed sleep apnea

Sleep paralysis – An inability to speak or move that occurs temporarily between sleep and wakefulness

Step therapy – An approach to prescribing medications where the patient must try the insurance company's preferred medication first

REFERENCES

1. Sleep and Sleep Disorders: Basics About Sleep. Centers for Disease Control and Prevention. https://www.cdc.gov/sleep/about_sleep/index.html Accessed 21 July 2022.
2. Colten HR, Altevogt BM. Extent and Health Consequences of Chronic Sleep Loss and Sleep Disorders. In: Sleep Disorders and Sleep Deprivation: An Unmet Public Health Problem. Washington, DC: National Academies Press; 2006.
3. Why Sleep Matters: The Economic Costs of Insufficient Sleep. RAND Corporation. https://www.rand.org/pubs/research_reports/RR1791.html Accessed 21 July 2022.
4. Sleep Topics. Sleep Foundation. <https://www.sleepfoundation.org/how-sleep-works/sleep-facts-statistics> Accessed 21 July 2022.
5. Schwartz JR, Roth T, Hirshkowitz M, Wright KP. Recognition and Management of Excessive Sleepiness in the Primary Care Setting. *Prim Care Companion J Clin Psychiatry*. 2009;11(5):197-204.
6. Duffy JF, Cain SW, Chang AM, et al. Sex Difference in the Near-24-hour Intrinsic Period of the Human Circadian Timing System. *Proc Natl Acad Sci U S A*. 2011 Sep 13;108 Suppl 3(Suppl 3):15602-15608.
7. Worley SL. The Extraordinary Importance of Sleep: The Detrimental Effects of Inadequate Sleep on Health and Public Safety Drive an Explosion of Sleep Research. *P T*. 2018 Dec;43(12):758-763.
8. Ayub S, Won CHJ. Obstructive Sleep Apnea in Women. *Journal of Sleep Medicine*. 2019;16(2):75–80.
9. Rising Prevalence of Sleep Apnea in U.S. Threatens Public Health. American Academy of Sleep Medicine. <https://aasm.org/rising-prevalence-of-sleep-apnea-in-u-s-threatens-public-health/> Accessed 21 July 2022.
10. Narcolepsy. Sleep Foundation. <https://www.sleepfoundation.org/narcolepsy> Accessed 21 July 2022.
11. Won C, Mahmoudi M, Qin L, Purvis T, Mathur A, Mohsenin V. The Impact of Gender on Timeliness of Narcolepsy Diagnosis. *J Clin Sleep Med*. 2014 Jan 15;10(1):89-95.
12. Idiopathic hypersomnia. UpToDate. <https://www.uptodate.com/contents/idiopathic-hypersomnia> Accessed 21 July 2022.
13. Dunne L, Patel P, Maschauer EL, Morrison I, Riha RL. Misdiagnosis of Narcolepsy. *Sleep Breath*. 2016 Dec;20(4):1277-1284.
14. Morse AM, Sanjeev K. Narcolepsy and Psychiatric Disorders: Comorbidities or Shared Pathophysiology? *Med Sci (Basel)*. 2018 Feb 15;6(1):16.
15. Identifying Narcolepsy Symptoms Is Important. Narcolepsy Link. <https://www.narcolepsylink.com/screening-and-diagnosis/recognizing-symptoms/> Accessed 21 July 2022.
16. Thorpy MJ, Hiller G. The Medical and Economic Burden of Narcolepsy: Implications for Managed Care. *Am Health Drug Benefits*. 2017 Jul;10(5):233-241.
17. D'Anselmo A, Agnoli S, Filardi M, et al. Creativity in Narcolepsy Type 1: The Role of Dissociated REM Sleep Manifestations. *Nat Sci Sleep*. 2020 Dec 17;12:1191-1200.
18. Barker EC, Flygare J, Paruthi S, Sharkey KM. Living with Narcolepsy: Current Management Strategies, Future Prospects, and Overlooked Real-Life Concerns. *Nat Sci Sleep*. 2020 Jul 16;12:453-466.
19. Narcolepsy. Division of Sleep Medicine at Harvard Medical School. <https://sleep.hms.harvard.edu/education-training/public-education/sleep-and-health-education-program/sleep-health-education-1> Accessed 21 July 2022.
20. Black J, Reaven NL, Funk SE, McGaughey K, Ohayon M, Guilleminault C, et al. The Burden of Narcolepsy Disease Study: Health-care Utilization and Cost Findings. *Sleep Medicine*. 2014;15(5):522–529.
21. Narcolepsy Fact Sheet. National Institute of Neurological Disorders and Stroke. <https://www.ninds.nih.gov/health-information/patient-caregiver-education/fact-sheets/narcolepsy-fact-sheet> Accessed 21 July 2022.
22. Narcolepsy and Pregnancy. European Narcolepsy Network. <https://www.eu-nn.com/narcolepsy-and-pregnancy/> Accessed 21 July 2022.
23. Maurovich-Horvat E, Kemlink D, Högl B, et al. Narcolepsy and Pregnancy: A Retrospective European Evaluation of 249 Pregnancies. *J Sleep Res*. 2013 Oct;22(5):496-512

NARCOLEPSY EDUCATION AND SUPPORT GROUPS

Narcolepsy Education

- American Academy of Sleep Medicine: <https://aasm.org/>
- Hypersomnia Foundation: <https://www.hypersomniafoundation.org>
- Know Narcolepsy <https://knownarcolepsy.com>
- Narcolepsy Network: <https://narcolepsynetwork.org>
- National Sleep Foundation: www.sleepfoundation.org
- NORD (National Organization for Rare Disorders): www.rarediseases.org
- Project Sleep: www.project-sleep.com
- Sleep Health Education Harvard: <https://sleep.hms.harvard.edu/education-training/public-education/sleep-and-health-education-program/sleep-health-education-1>
- Wake Up Narcolepsy: <https://www.wakeupnarcolepsy.org>

Safety Resources

- Guide to Drowsy Driving: <https://sr22insurance.net/the-ultimate-guide-to-drowsy-driving/>
- Narcolepsy Safety: <https://healthysleep.med.harvard.edu/narcolepsy/living-with-narcolepsy/safety>
- Sleep/Cataplexy Diary: <https://www.narcolepsylink.com/static/media/sleep-cataplexy-diary.pdf>

Sleep and Meditation Apps

- Calm: <https://www.calm.com>
- Headspace: <https://www.headspace.com>
- Insight Timer: <https://insighttimer.com>

School and Work Resources

- Narcolepsy Goes to School: <https://www.facebook.com/WakeUpNarcolepsyNarcolepsyGoestoSchool/>
- Navigating School with Narcolepsy: <https://project-sleep.com/wp-content/uploads/2021/08/Navigating-School-with-Narcolepsy-Toolkit.pdf>
- Wake Up and Learn: <https://wakeupandlearn.org/>
- Job Accommodation Network: <https://askjan.org/disabilities/Sleep-Disorder.cfm>
- Narcolepsy at Work: <https://healthysleep.med.harvard.edu/narcolepsy/living-with-narcolepsy/at-work>
- Narcolepsy Network for Employees: <https://narcolepsynetwork.org/resources/for-employees/>

Financial Resources

- AASM Financial Assistance: <https://sleepeducation.org/patients/financial-assistance/>
- Needy Meds: <https://www.needymeds.org/>
- Jack & Julie Narcolepsy Scholarship: <https://project-sleep.com/narcolepsy-scholarship/>

Navigating Health Insurance

- Consumer Assistance Program: www.cms.gov/ccio/resources/consumer-assistance-grants#statelisting
- Employee Benefits Security Administration: www.dol.gov/agencies/ebsa/about-ebsa/ask-a-question/ask-ebsa
- State Health Insurance Assistance Program: www.seniorsresourceguide.com/directories/National/SHIP/

Other Resources

- ClinicalTrials.gov: <https://www.clinicaltrials.gov/>
- Find a Sleep Center: <https://sleepeducation.org/sleep-center/>
- More Than Tired Find a Sleep Specialist: <https://www.morethantired.com/find-a-narcolepsy-sleep-specialist/>
- NIH Sleep Health: <https://www.nhlbi.nih.gov/health-topics/education-and-awareness/sleep-health>

This worksheet allows you to keep track of your sleep, symptoms, treatments, and other relevant details so that you can share a more complete picture of your experience with your health care providers. With a better understanding of your narcolepsy experience, you and your health care providers can design and/or adjust a care plan tailored to your needs and goals.

Month & Dates:

Complete this section at night, before bed, indicating the QUANTITY and TIME OF DAY:							
	Sun	Mon	Tue	Wed	Thu	Fri	Sat
Caffeinated beverages:							
Alcoholic drinks:							
Naps (include duration):							
Exercise (include duration):							
Cataplexy attacks:							
Can you identify what triggered the attacks?							
Level of sleepiness* throughout the day:							
What were you doing when sleepiness was the strongest?							
New medication or treatment taken:							
Bedtime:							

*Sleepiness Scale:	1-2	3-4	5-6	7-8	9-10
	Alert and fully functional	Relaxed and awake, but not fully alert	Foggy, reduced level of function	Sleepy with the desire to lie down	Fighting sleep, unable to remain awake

Complete this section after waking up in the morning:							
	Mon	Tue	Wed	Thu	Fri	Sat	Sun
Time awake:							
Did you wake up during the night?							
Time it took to fall back sleep:							

Notes (Including other symptoms experienced throughout the week, such as sleep paralysis or hallucinations):