

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



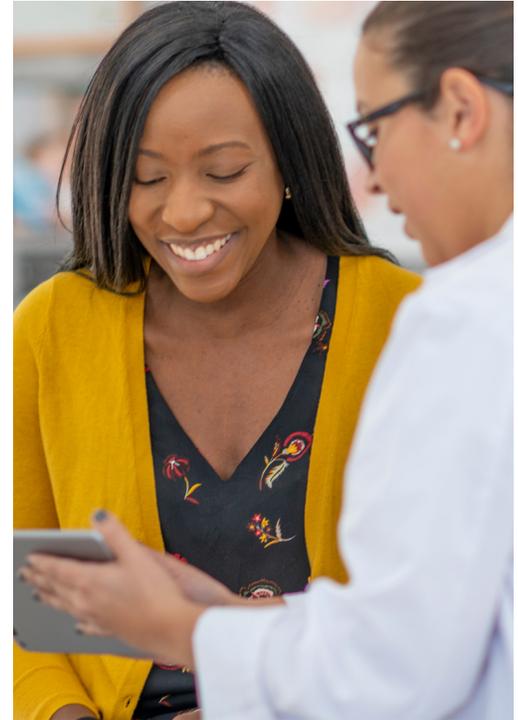
Ear, nose, and throat (ENT) provider



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
- **Coinsurance** – 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.