Narcolepsy and You

Understanding and Managing Your Disorder

Understanding Narcolepsy

Are you often very sleepy during the day? Do you sometimes fall asleep by accident? Is your nighttime sleep disrupted or not restful? Do you wake feeling unrefreshed? If you answered yes to any of these questions, you may have **narcolepsy,** a sleep-wake disorder that can affect you 24 hours a day. There is no cure for narcolepsy. But with proper care, its symptoms can be reduced. This booklet provides information about narcolepsy and tips on how to live a healthy life with this often misunderstood condition.

What Is Narcolepsy?

Narcolepsy is a chronic (lifelong) neurologic (brain-related) condition. **Excessive daytime sleepiness** is its most common symptom. If you have narcolepsy, you do not need more sleep than other people. Rather, you are not able to maintain normal sleep and wake states. The resulting irregular sleep patterns can make you extra sleepy during the day. These patterns can also keep you from getting the quality sleep you need at night.

Why Is Narcolepsy a Problem?

Many people don't understand narcolepsy. Some may think your sleepiness is due to laziness or lack of attention. Others may think falling asleep during the day is not a big problem. But narcolepsy is a serious medical disorder that can affect you in many ways. It can keep you from getting the nighttime sleep your body needs to stay healthy. It can cause emotional and social difficulties. It can put your job or education at risk. And it can lead to mistakes and accidents that can endanger your health and even your life. So it's important to get proper treatment.

This booklet is not intended as a substitute for professional medical care. Only your doctor can diagnose and treat a medical problem.

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Who Gets Narcolepsy?

Narcolepsy patients do not fit any specific profile. The disorder is found in all types of people around the world. Males and females have it in equal numbers.

How Many People Have It?

In the U.S., nearly 200,000 people may have narcolepsy. But only a small percentage know they have it. Narcolepsy is about as common as multiple sclerosis and Parkinson's disease. You hear less about it because it is so misunderstood.

Is It Hereditary?

Although there is a genetic component to narcolepsy, most narcolepsy patients have no known relative with the disorder. Research has found that if a person has certain genes, he or she is more likely to have narcolepsy. However, having these genes does not always mean that narcolepsy will result.

When Does It Appear?

In most cases, narcolepsy symptoms first appear when patients are between the ages of 10 and 25. But they can appear at any age and in any order. Many patients find that symptoms get worse as they get older. Other patients find that symptoms lessen over time, although they never go away completely.

Symptoms of Narcolepsy

Narcolepsy symptoms vary widely from person to person. Some happen during the day. Others appear at night.

Daytime Symptoms

- **Excessive daytime sleepiness (EDS)** affects 100 percent of narcolepsy patients. With EDS, patients feel abnormally sleepy at different times throughout the day. They may also fall asleep quickly and at inappropriate times, such as while they are eating or talking. These unplanned sleep episodes are called **"sleep attacks."**
- **Cataplexy** affects 60 to 100 percent of narcolepsy patients. It involves sudden loss of muscle tone or strength. It can result in drooping eyelids and face, buckling of the knees, or paralysis of the whole body. Cataplexy attacks usually last less than 30 seconds. They are mostly triggered by laughter or sudden feelings of anger, fear, or surprise.
- **Automatic behavior** involves patients seeming to "fall asleep" while they are awake. They may perform routine tasks and not remember them afterward. They may also jump from topic to topic while speaking, or suddenly stop talking in the middle of a discussion.

Nighttime Symptoms

- **Disrupted nighttime sleep (DNS)** affects 60 to 90 percent of narcolepsy patients. It is due to patients' irregular sleep cycles. Patients wake up often throughout the night, and can have trouble getting back to sleep. DNS can prevent patients from getting enough sleep, and can worsen EDS.
- **Sleep paralysis** occurs in about 60 percent of narcolepsy patients. It usually occurs when the patient is falling asleep or waking up. The person is conscious but cannot move or speak. Episodes can last a few seconds or several minutes. They can cause panic in a patient if he or she is not familiar with this symptom.
- **Hallucinations** affect up to 66 percent of narcolepsy patients. They are vivid, often frightening dreams that happen when the patient is falling asleep or waking up. They can involve images, sounds, touch, and smell, and can seem very real. They often occur at the same time as sleep paralysis.

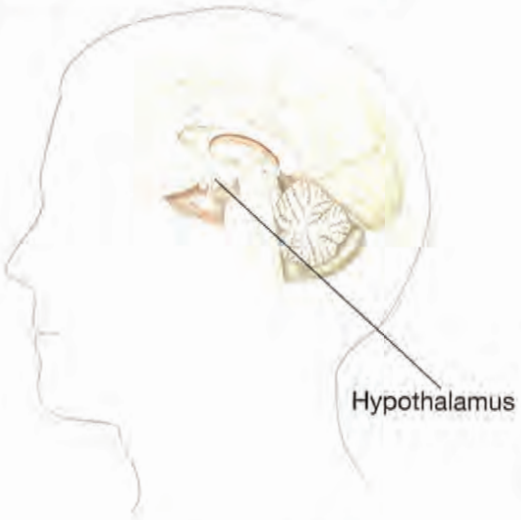
Why Narcolepsy Occurs

Research continues into the causes of narcolepsy. Advances in the last decade have shown that the disorder is caused by problems in brain chemistry.

Lack of Hypocretins

Most cases of narcolepsy seem to be linked with low levels of **hypocretins.** These are chemicals produced in the brain. Hypocretins are involved with several brain functions, including the sleep-wake cycle. They help a person wake up and stay awake.

- **Why are hypocretins lacking?** Studies have shown that low hypocretin levels are caused by the loss of brain cells that produce these chemicals. Some scientists think that an autoimmune reaction is involved. In an autoimmune reaction, a person's immune system attacks the body itself instead of an outside invader. In this case, the immune system of narcolepsy patients may mistakenly attack the cells in the brain that produce hypocretins.
- **What is triggering the problem?** The specific trigger or triggers that cause the autoimmune response are not yet known. Possible triggers include viruses, exposure to toxins, accidents, stress, drug use, abrupt changes in sleep patterns, and hormonal changes.



Hypocretins are secreted by the hypothalamus, a region in the center of the brain.

Understanding Sleep Cycles

Everybody goes through certain stages during sleep. But the timing and order of these stages differ greatly between healthy and narcoleptic sleepers.

Healthy Sleepers

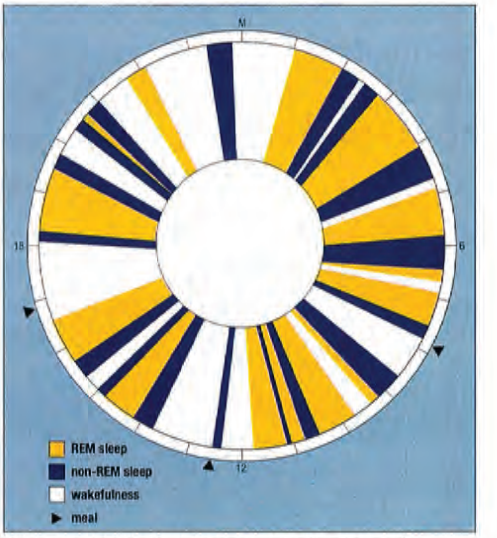
Healthy sleepers usually sleep between 6 and 8 hours during the night. While sleeping, they go through several stages. Stage 1 and 2 consist of lighter sleep. Stage 3 and 4 are comprised of deeper, restorative sleep (thought to restore the body's energy and immune system). These four stages are known as **non-REM (rapid eye movement)** sleep, or quiet sleep. Brain waves slow down during non-REM sleep. Then, after about 90 minutes, the sleeper enters **REM,** or active, sleep. During this stage, brain waves speed up. Dreams occur and muscles are paralyzed (most likely to keep sleepers from acting out their dreams). Sleepers may cycle through these stages 4 or 5 times during the night.

Sleep Stages of a Healthy Sleeper

Sleep Stage	Activity	Percentage of Nighttime Sleep
Non-REM Sleep		
Stage 1 *(Transition from wakefulness to sleep; the lightest stage of sleep)*	• Brain activity levels are high	5–10
Stage 2 *(First stage of true sleep; also called intermediate sleep)*	• Breathing and heart rates slow • Brain activity levels decrease	40–50
Stage 3 and 4 *(Occur mostly in the first half of the night; also called deep or restorative sleep)*	• Blood pressure and heart rate decrease further	20
REM Sleep		
(Occurs 4 or 5 times per night)	• Breathing and heart rates speed up • Brain activity speeds up and can equal or exceed that of waking hours • Eyes move quickly back and forth (most other muscles are paralyzed) • Dreaming occurs	20–25

Narcoleptic Sleepers

Narcoleptic sleepers typically do not get 6 or 8 hours of sleep all at once. Instead, their sleep cycle is spread out over all 24 hours of the day. They may sleep a normal amount during this time, but cannot control the timing of sleep. Often they get only brief periods of sleep during the night. Then they need to make up the rest during the day, which can result in excessive sleepiness and sleep attacks.



This graphic illustrates a narcoleptic sleeper's irregular sleep-wake cycle during a 24-hour period.

Broughton, R. & M. Mamelak. Gamma-hydroxy-butyrate in the treatment of narcolepsy: A preliminary report. *Advances in Sleep Research*. 1976; 3:659-667. Spectrum Publications, Inc.

Figure reprinted with permission from Roger Broughton, MD.

The length and order of sleep stages are also different for narcoleptic sleepers. Stage 1 sleep is increased, and Stage 3 and 4 sleep is greatly decreased. Upon falling asleep, narcoleptic sleepers enter REM sleep almost right away. This is called a **sleep onset REM period (SOREMP).** These SOREMPs are often brief. Because of these abnormal sleep patterns, narcoleptic sleepers rarely get enough of most stages of sleep.

Why Is a Healthy Sleep Cycle Important?

Adequate sleep is vital for everyone. Research shows that REM sleep may aid in memory, learning, and mood regulation. Certain stages of non-REM sleep may help our bodies restore energy and repair damaged cells. Researchers still don't know for sure the full role of sleep.

However, they do know that not getting enough sleep can be harmful. Even healthy sleepers who get 1 or 2 fewer hours of sleep than usual show signs of physical and mental problems. These can include:

- Decreased attention, poor mood, and low energy.
- Being prone to accidents and mistakes.
- Impaired immune function.
- Increased risk of heart disease and type 2 diabetes.
- Reduced quality of life.

So it's easy to see why getting treatment for narcolepsy is important.

Do You Have Narcolepsy?

If sleep problems affect your home and work life, see your doctor. He or she can help determine whether you have narcolepsy. Many healthcare providers are not familiar with sleep disorders, so your doctor may refer you to a sleep clinic.

Epworth Sleepiness Scale (ESS)

To help prepare for your doctor visit, you can take the ESS. This test measures daytime sleepiness by gauging your level of sleepiness during certain activities. For each item below, rate your level of sleepiness from 0 to 3. Then add your score, and discuss the results with your doctor.

0 = would never doze
1 = slight chance of dozing
2 = moderate chance of dozing
3 = high chance of dozing

Sitting and reading
0 ❑ 1 ❑ 2 ❑ 3 ❑

Watching television
0 ❑ 1 ❑ 2 ❑ 3 ❑

Sitting inactive in a public place, such as a theater or a meeting
0 ❑ 1 ❑ 2 ❑ 3 ❑

As a passenger in a car for an hour without a break
0 ❑ 1 ❑ 2 ❑ 3 ❑

Total score: _____

Lying down to rest in the afternoon
0 ❑ 1 ❑ 2 ❑ 3 ❑

Sitting and talking to someone
0 ❑ 1 ❑ 2 ❑ 3 ❑

Sitting quietly after a lunch without alcohol
0 ❑ 1 ❑ 2 ❑ 3 ❑

In a car while stopped for a few minutes in traffic
0 ❑ 1 ❑ 2 ❑ 3 ❑

If your score is 10 or higher, you should discuss these results with your doctor.

Epworth Sleepiness Scale used under license.
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Additional Narcolepsy Symptoms

To assess yourself for other narcolepsy symptoms, answer the following questions. If you answer yes to one or more, you should consult your doctor.

I sometimes experience muscle weakness or a loss of muscle strength when I laugh or get angry.
Yes ❑ No ❑

If yes to the above question: I sometimes avoid emotional situations because of these episodes of muscle weakness/loss of muscle strength.
Yes ❑ No ❑

I have no problems falling asleep at night, but have trouble sleeping through the night.
Yes ❑ No ❑

I sometimes experience a brief period upon waking or falling asleep where I want to get up but cannot move a muscle or speak.
Yes ❑ No ❑

I often have very vivid and/or frightening dreams when I sleep.
Yes ❑ No ❑

Talking to Your Doctor

To begin your assessment for narcolepsy, your doctor will give you a thorough physical exam, take a medical history, and review any medications you are taking. Your doctor will also want a full description of your sleep problems. A sleep diary that details your recent sleep patterns can help.

A Difficult Diagnosis

Be sure to clearly explain your problems and concerns to your doctor. Narcolepsy can be hard to diagnose. For many patients, the process can take years. This is because symptoms tend to appear slowly, often over many years. Also, healthcare providers may not know about sleep disorders. Or, they simply may not recognize the signs of narcolepsy. The disorder is especially hard to diagnose because there is no one symptom that indicates it. For instance, EDS is present in all narcolepsy cases. However, it can also be caused by many other conditions, such as depression, chronic illness, and sleep apnea. So, the best way to diagnose narcolepsy is with certain sleep tests.

Act Early

See a doctor at the first signs of narcolepsy. This is especially important for children. The younger a child is at diagnosis, the sooner treatment can begin. This can help prevent learning difficulties that can affect school performance. It can also help avoid other problems caused by narcolepsy, such as behavioral issues and depression.

Tests to Confirm a Diagnosis

Several tests are used to check for narcolepsy. The main tests are **polysomnography (PSG)** and the **multiple sleep latency test (MSLT).** These tests are normally done at a sleep disorders center.

PSG

This is an overnight test that is done while you sleep. PSG measures heart and breathing rates, electrical activity in the brain, nerve activities in the muscles, and eye movements. It can help reveal abnormal sleep patterns and rule out other conditions. An overnight PSG is typically done the night before an MSLT.

MSLT

During this test, you are asked to take 4 or 5 short naps over the course of a day. The MSLT measures how long it takes you to fall asleep. It also checks whether REM sleep occurs at abnormal times in the sleep cycle. The MSLT is the most widely accepted test for confirming a diagnosis of narcolepsy.

Other Tests

Other tests that may help diagnose narcolepsy include:

- **Testing spinal fluid for hypocretins.** This new test measures the level of hypocretins in spinal fluid. Low levels are almost always a sign of narcolepsy.
- The **maintenance of wakefulness test (MWT).** This test measures your ability to stay awake during 20-minute periods of lying down in a dark, quiet room.

Treating Narcolepsy

If your diagnosis confirms narcolepsy, your doctor or sleep specialist will discuss treatment with you. Treatment usually consists of medication and behavior changes. Most likely, your treatment will not relieve all symptoms. It may take weeks or months to manage your symptoms. Getting started on proper treatment can help you feel better and live a more normal life.

Medication

Talk to your doctor or sleep specialist about whether medication is a good choice for you. Effective prescription medications may significantly improve the multiple symptoms associated with narcolepsy.

Behavior Changes

To help manage EDS and DNS, it is important to practice healthy sleep habits. This is also known as **sleep hygiene.** Here are tips that may help you sleep better at night and be more alert during the day.

- **Find out if daily naps help you.** Many narcolepsy patients benefit from naps. Some take several short naps of 10 to 20 minutes each. Others find one long nap more helpful. Make sure naps do not interfere with your nighttime sleep.
- **Go to bed and get up at the same time each day.** This can help get your body on a regular sleep schedule.
- **Use your bed only for sleep and sex.** This can help you associate your bed with sleep.
- **Relax before bedtime.** Take a warm bath, practice yoga, or meditate. This can help tell your body it's time to settle down and sleep.
- **Avoid caffeine, alcohol, and nicotine late in the day.** They can keep you awake at night.
- **Avoid bright lights in the hour before bedtime.** Bright light from computer screens or lamps can reset your "body clock," making it harder to fall asleep.
- **Exercise regularly.** It may help you feel more alert during the day and sleep better at night. Avoid strenuous exercise for 2 to 4 hours before bedtime.

The Emotional Side of Narcolepsy

Narcolepsy can impact every aspect of your life. Dealing with it can take a toll on your mental and emotional health. If you recognize the causes and get the help you need, you can feel better.

The Problems

Emotional problems affect many people with narcolepsy. So if you have them, you're not alone. Common problems include:

- **Isolation.** Narcolepsy may cause you to withdraw emotionally. You may avoid others because they don't understand what you're going through, or because symptoms embarrass you. Also, you may keep to yourself to prevent having strong emotions, which can cause cataplexy attacks.
- **Low self-esteem.** Having trouble functioning in your daily life can cause you to doubt yourself and your abilities. Your self-esteem can also be affected if others mistake your symptoms for laziness or lack of discipline.
- **Depression.** The isolation and low self-esteem often caused by narcolepsy can lead to depression. Common symptoms include feeling down most of the time, losing pleasure in things you used to enjoy, and having trouble focusing, remembering, or making decisions.
- **Sexual problems.** Narcolepsy and medications taken for it can cause low sex drive and impotence. Patients may even fall asleep during sex. These things can be hard for your partner to understand, and it can cause you to avoid physical intimacy.

Tips for Family and Friends

The life of a person with narcolepsy isn't easy. If you have a family member or friend with narcolepsy, here are ways you can help.

- **Learn** all you can about narcolepsy. A good knowledge of the condition can help you understand what your loved one is going through.
- **Support** your loved one. Let him or her know you want to help. Offer to join a support group together, or provide a ride when he or she can't drive.
- **Listen** to your loved one. Don't judge, and don't offer ways to "cure" the condition. Just let him or her talk.

Getting Help

If you have any of these problems, talk to your doctor or healthcare provider. Discuss emotional issues that concern you, as well as any related physical problems. Your doctor can suggest ways to help you cope, such as:

- **Sharing with others.** Talk about your disorder with your family, friends, your other healthcare providers, even your neighbors. Talking about it can help others understand what narcolepsy is and what you're dealing with, and it can teach them how to help when your symptoms occur.
- **Seeking counseling.** Individual counseling can give you insight into your emotions, new tools for dealing with problems, and emotional support. Family and marriage counseling can help you and those closest to you work together to live more comfortably with your condition.
- **Dealing with depression.** Depression is a serious illness. If you are diagnosed with it, your doctor may suggest an antidepressant or therapy. He or she may also give you tips to help you feel better. These can include spending time with others, exercising and eating well, and taking life one day at a time.
- **Joining a support group.** In a support group, you can compare experiences with others who have your condition. You can share coping strategies. You can find empathy and understanding that may be hard to find elsewhere. Most importantly, you can be reminded that you're not the only person coping with narcolepsy.
- **Joining a national support organization.** Educational information is available from these organizations (see the back of this booklet). It can help you to better understand, manage, and cope with your symptoms.

Living with Narcolepsy

Narcolepsy can affect your life at work, at school, and at home. The following ideas can help you face challenges and live well with your condition.

Working

Without treatment, people with narcolepsy can have trouble performing their work duties, or even holding a job. With proper treatment, most can have a successful career in almost any field. Here are tips that can help.

- **Find work that works for you.** Avoid jobs that involve shift work, irregular schedules, long commutes, and lots of driving. Look for jobs that keep you busy, let you work with others, and allow a flexible schedule.
- **Know your rights.** The Americans with Disabilities Act (ADA) and state laws require most employers to reasonably accommodate your condition. For instance, you should be able to take short naps, change your work schedule, or modify your duties, if needed. Learn more about work-related issues at the website for the U.S. Equal Employment Opportunity Commission: www.eeoc.gov.

Learning

Younger and older students with narcolepsy can have problems with memory and attention. These can result in learning or developmental disabilities, which can make school difficult.

- **For children in grades K-12:** Parents should tell teachers and school nurses about the condition and medications the child is taking. The Individuals with Disabilities Education Act (IDEA) and state laws require the child's school to accommodate his or her learning needs.
- **For college students:** Tell your instructors about your condition so they'll understand if you have symptoms during class. Seek out services available to physically, learning, and developmentally disabled students. If possible, nap before classes and avoid taking classes during the sleepiest part of your day. Also, choose small classes, and study in a group to help you retain knowledge.

Staying Safe

People with narcolepsy may lose physical control at any time. Therefore, safety is a real concern.

- **Driving.** Excessive sleepiness is the second biggest cause of auto accidents in the U.S. The good news is that people with narcolepsy who take medication have the same accident rates as other drivers. Still, some states restrict driving with narcolepsy. If you live in a state that has such laws, a letter from your doctor stating that you are treated and safe to drive may help you keep your license.

  If you drive, pay close attention to sleepiness. Do not drive while drowsy. If you become drowsy, find a safe place to pull over and take a short nap.

- **Accidents.** Sudden sleep episodes and cataplexy attacks can cause serious accidents. Even activities like cooking or walking down a flight of stairs can be dangerous if symptoms occur. So make sure you get proper treatment for your symptoms. Avoid risky situations, such as climbing ladders, until your symptoms are under control.

Keeping a Healthy Weight

Many people with narcolepsy are overweight. This may be caused in part by a low activity level due to excessive sleepiness. It may also have to do with changes in brain chemistry that affect eating habits and metabolism. No matter the cause, keeping a healthy weight is as important for narcolepsy patients as it is for others. The following can help you manage your weight and improve your overall health:

- **Exercise.** Try to exercise regularly. Exercise can help improve alertness. It can also help curb appetite and control weight gain.
- **Proper diet.** Eat lots of fruits, vegetables, and whole grains, and limit processed foods. Eating a variety of nutritious foods can help you avoid gaining excess weight, help prevent illness, and make you feel better. Keep in mind that foods high in sugar and refined carbohydrates can cause sleepiness. Limiting carbohydrates until evening may help improve wakefulness during the day.

A Healthy Life

Narcolepsy is a serious, around-the-clock sleep-wake disorder that can affect your physical and mental health. But it can be managed. Learn as much as possible about your condition and get proper treatment. With a little knowledge, some behavior changes, and medication, you can live a healthier, more normal life.

For More Information

To find out more about narcolepsy, contact the following resources:

Narcolepsy Network
888-292-6522
www.narcolepsynetwork.org

National Sleep Foundation
www.sleepfoundation.org

American Academy of Sleep Medicine
www.sleepeducation.com

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