

AN INTRO TO  
***NARCOLEPSY***

*An introductory guide to narcolepsy:  
What is narcolepsy? Definition, symptoms, causes  
and treatment*

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CHAPTER ONE

# *Narcolepsy overview*



# SLEEP – WAKE CYCLE

## What is a sleep – wake cycle?

A sleep-wake cycle is a 24 hour internal clock which regulates sleep. If there is inability to regulate this internal clock it can hinder certain sleep stages and cycles. As a result, sufferers have an extreme tendency to fall asleep whenever in relaxing surroundings.





# NARCOLEPSY QUICK FACTS

- Affects men and women equally
- Symptoms present themselves between 7 and 25 years old
- Under-recognized and under-diagnosed condition
- Most cases are sporadic, with no known family history
- Narcolepsy is a life long condition
- Currently incurable but can be managed with medicine and life style changes.



CHAPTER TWO

*SYMPTOMS*



# NARCOLEPSY

*Narcolepsy Symptoms*

## **NARCOLEPSY SYMPTOMS:**

- Excessive Daytime Sleepiness
- Cataplexy
- Hallucinations
- Sleep Paralysis
- Disturbed Nocturnal Sleep
- Leg jerks, Nightmares, and Restlessness



## EXCESSIVE DAYTIME SLEEPINESS

Normally, **excessive daytime sleepiness (ESD)** is the first symptom to appear in people who have narcolepsy.

Unless they're being treated for the disorder, the need to sleep can be overwhelming for narcolepsy patients: those with narcolepsy are prone to falling asleep while engaged in conversation, driving, eating dinner, or at other inappropriate times. The sleepiness occurs in spite of a full night's sleep and may persist throughout the day.



# CATAPLEXY

**Cataplexy** is the second symptom after EDS.

Cataplexy is an abrupt temporary loss of voluntary muscular function and tone. Sparked initially by an emotional stimuli such as laughter, pleasure, or anger.



It can involve all muscles and result in collapse (inability to stand) or an episode may only affect certain muscle groups and result in:

- drooping eyelids
- slurred speech
- buckling of the knees
- weakness in the arms

Even in the most severe attacks, sufferers remain fully conscious, entirely aware of what is occurring and happening around them.

# HALLUCINATIONS

Often times hallucinations are associated with narcolepsy. They tend to be frightening and very vivid for those who experience them.

Sleep related hallucinations can occur in as many as 25% of people, most commonly found in women, young adults and teens.



**Hypnagogic hallucinations** occur during the transition from wakefulness to sleep (falling asleep).

**Hypnopompic hallucinations** are hallucinations from sleep to wakefulness (waking up) and may also be accompanied by sleep paralysis.

These hallucinations are bizarre, often frightening dream-like experiences that incorporate his or her real environment. 11

# SLEEP PARALYSIS



**Sleep Paralysis** is a temporary inability to move when waking up from sleep. These episodes can last for a few seconds up to several minutes.

During REM sleep brain activity increases and most people experience dreaming. Voluntary muscles become paralyzed (atonia) as a response to keep our bodies from acting out our dreams, and possibly harming ourselves or our bed partners.

Sleep paralysis occurs when people awake before the REM stage has been completed. This leaves sufferers conscious of their surroundings but still unable to move or speak until the REM cycle has been completed.

## DISTURBED NOCTURNAL SLEEP

It may seem counterintuitive to believe that sufferers of narcolepsy would have any trouble sleeping at night, but one of the most common symptoms is disturbed nocturnal sleep also known as fragmented sleep.

Just as people with narcolepsy have trouble staying awake during the day, they often have difficulty staying asleep at night. Sufferers can wake up to four or five times up in a night for up to 10 or 20 minutes with no clear reason.





CHAPTER THREE

*DIAGNOSIS*



## DIAGNOSING NARCOLEPSY

Your primary care physician may be able to make a preliminary diagnosis of narcolepsy based on symptoms of EDS and cataplexy.

For a comprehensive diagnosis of narcolepsy you will need to have a couple of specialized tests performed at a sleep clinic or a sleep lab.

These two tests used in conjunction to diagnose narcolepsy are:

- **Polysomnogram (PSG)**
- **Multiple sleep latency test (MSLT)**

## POLYSOMNOGRAM (PSG)

A **polysomnogram (PSG)** is an overnight sleep study where patients are hooked up to a variety of equipment that record brain activity, eye movements, heart rate, blood pressure, oxygen levels, body movement, etc. PSGs are used to document any abnormalities in a patient's sleep patterns and cycles.

For a PSG used in diagnosing narcolepsy it also helps to rule out any other sleep disorders that may be causing symptoms (such as obstructive sleep apnea causing EDS) or to document any comorbid sleep disorders.

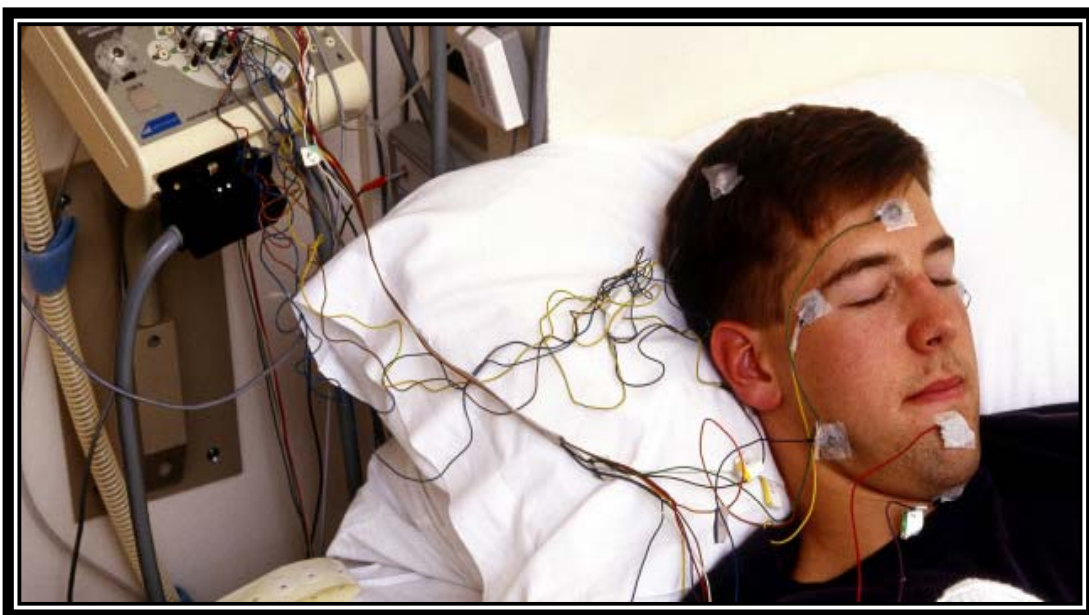




# MULTI SLEEP LATENCY TEST (MSLT)

A **Multiple Sleep Latency Test (MSLT)** is a sleep study performed during the day to measure your tendency to fall asleep and how rapidly you fall asleep. A MSLT will generally follow a PSG to record whether you fall asleep during the test, and if so, which stages of sleep you enter.

During a MSLT you are generally given five 20-minute nap opportunities spaced 2 hours apart. A sleep technician monitors your brain activity and eye movements. Patients with narcolepsy often fall asleep and enter REM sleep very quickly.





CHAPTER FOUR

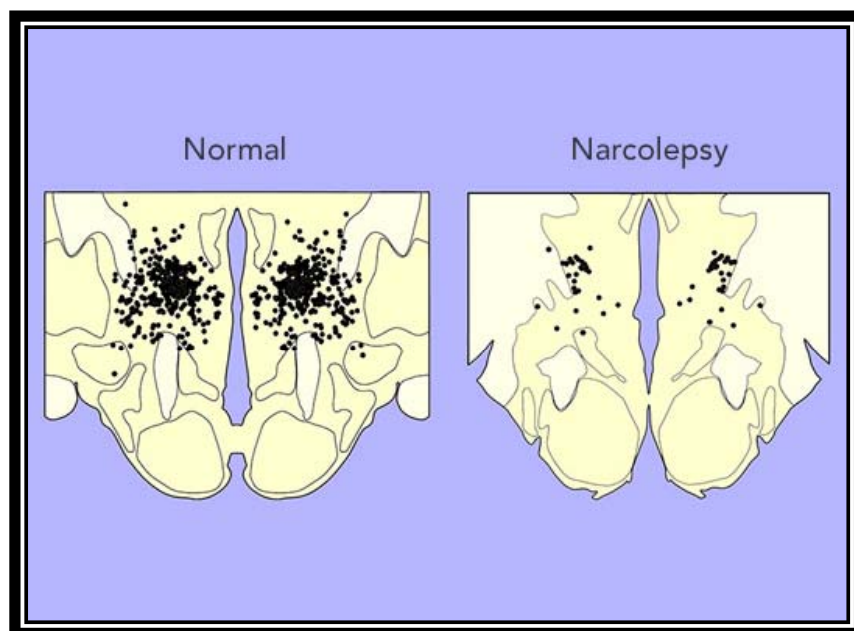
*TREATMENT*

# PRESCRIPTONS AND REMEDIES

Currently there is no cure for narcolepsy. However, with proper diagnosis and treatment many of the symptoms can be minimized or treated.

Research has discovered that a symptom of narcolepsy with cataplexy is caused by loss of hypocretins.

Hypocretins are important brain chemicals that regulate arousals, wakefulness and appetite. The picture below illustrates the number of hypocretin producing neurons in the brain of a normal patient compared with those of a narcoleptic patient with cataplexy.



HARVARD MEDICAL SLEEP MEDICINE



# STIMULANT TREATMENT

## Stimulants

Stimulants are the mainstay of drug treatment for narcolepsy. These drugs are used to stimulate the central nervous system to promote wakefulness and alertness.

Today these types of stimulants prescribed aren't considered as addictive or come with the highs and lows associated with older stimulants.

Yet, some side effects of stimulant treatment can include headache, nausea, irritability, nervousness, shakiness, heart palpitations, and nighttime sleep disruption.



# ANTIDEPRESSANT TREATMENT

## Antidepressants

Selective serotonin reuptake inhibitors (SSRI's) and serotonin and norepinephrine reuptake inhibitors (SNRI's) have been used to suppress REM sleep. Antidepressant therapy can alleviate symptoms of cataplexy, sleep paralysis, and hypnagogic hallucinations.

Antidepressants often produce fewer adverse side effects than stimulants,. They still can come with their own side effects such as impotence, high blood pressure, and digestive problems.



# SODIUM OXYBATE TREATMENT

## Sodium Oxybate

Sodium oxybate is a strong sedative that is administered at night and helps relieve symptoms of cataplexy and EDS.

Sodium oxybate is also known as GHB. It comes with serious safety concerns and distribution is heavily monitored, but is still considered safe for treating narcolepsy symptoms.

When following directions as intended sodium oxybate is used to promote sound sleep, diminish daytime sleepiness, and reduce incidences of cataplexy.

Side effects of sodium oxybate can include nausea, bedwetting (enuresis), and worsening of sleepwalking.

## LIFESTYLE & HOME REMEDIES

In addition to any medications prescribed by your doctor you can also make changes to your lifestyle and sleep environment to lessen narcolepsy reoccurrences.



**Take several short naps a day** (10-20 minutes) to alleviate excessive daytime sleepiness.

**Keep a consistent sleep schedule.** Go to sleep and wake up at the same times everyday, including weekends.

**Avoid caffeine and alcoholic beverages** 2-3 hours before bedtime as these substances can worsen symptoms.

**Get regular exercise.** Daily exercise 4-5 hours before bedtime can help improve quality of sleep as well as alleviate symptoms of daytime drowsiness.

# LIFESTYLE & HOME REMEDIES

**Try a relaxing routine just before bedtime.** A relaxing bath or reading a good book before bedtime can help promote better sleep at night.

**Talk to others about your condition.** Having the love and support from those close to you can go a long way in treatment.

Furthermore, your coworkers, employers, and teachers should also be aware of your condition to help accommodate your needs.

Support groups can also be helpful in connecting with others suffering from the same condition. At support groups you can also learn about the latest developments in medicine, get coping tips from others, other practical help, and even emotional support.





## TREATMENT

### *Most Important* - **BE SAFE**

Having a condition where maintaining wakefulness is difficult can prove to be extremely dangerous. Even during mundane activities like walking down stairs or grilling on a barbecue can quickly become life threatening if a sleep attack occurs.



Driving can be one of the most dangerous activities for sufferers with untreated narcolepsy as those with the disorder are 10 times more likely to have driving accidents than those without it.

Work with your doctor to establish a medication time to coincide with your driving schedule. And if at any time you begin to feel excessively sleepy, stop what you're doing and take a nap (if possible) or take an exercise break.



CHAPTER FIVE

*FAMOUS  
NARCOLEPTICS*



**Sir Winston Churchill** was the United Kingdom's Prime Minister during World War II and helped lead the UK to defeat their enemies.

“

*“You must sleep sometime between lunch and dinner... Take off your clothes and get into bed... You get two days in one. Well, at least one-and-a-half.”*

**Winston Churchill**

”



*Jimmy Kimmel is a comedian, executive producer and host of the late night talk show Jimmy Kimmel Live!.*

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*Truth be told, I'd rather have narcolepsy than not have it. When I get on a flight to Vegas, I'll fall asleep before the plane takes off and wake up after it's landed. I'm always very close to sleep.*

**Jimmy Kimmel**

”

# ***CONCLUSION***

## **WHAT TO DO NEXT?**

If you believe that your excessive daytime sleepiness, hallucinations, or other symptoms may be a sign of narcolepsy, the next step is to get help. Help can be found by a visit to your general practitioner or family doctor. Or you can contact a sleep clinic directly to work with a board certified sleep specialist to have your sleep study performed.

**If you live in Alaska and would like to have a sleep study performed, visit us online at [www.alaskasleep.com](http://www.alaskasleep.com) and look for the Self Referral form under the Patients Tab.**

