DOCTOR DISCUSSION GUIDE

Managing Narcolepsy

Narcolepsy is a chronic sleep condition characterized by severe daytime sleepiness, making it difficult for people with this disorder to stay awake for long periods during the day. It can cause significant disruptions to a person's daily functioning.

Vocabulary to Know

Your doctor might mention these common terms. Here's what they mean.

Narcolepsy Type 1	Occurs when low levels of hypocretin (a brain chemical), excessive daytime sleepiness, and a sudden loss of muscle tone are present.
Narcolepsy Type 2	Characterized by normal levels of hypocretin, no loss of muscle tone, and excessive daytime sleepiness.
Hypocretin	A brain chemical that helps regulate the sleep-wake cycle.
Secondary Narcolepsy	Can develop as a result of a brain injury. When the area of the brain that regulates sleep (hypothalamus) is injured, narcolepsy can result.
Sleep-Wake Cycle	The body's sleep pattern that regulates the number of hours a person sleeps and the time they spend awake during a 24-hour period.
REM Sleep	REM sleep, or rapid eye movement sleep, is the final sleep stage. During REM sleep, the eyes move rapidly but the body barely moves due to low muscle tone. It is the time during sleep that dreams occur.
Polysomnogram	An overnight sleep study used to diagnose sleep disorders that is conducted at a sleep center. It is performed by recording the brain activity, eye movement, muscle tone, body movements, breathing patterns, and heart rhythm of a person while they are sleeping, using sensors that are attached to various parts of the body.
Multiple Sleep Latency Test	This test takes place the day after a polysomnogram. It is used to monitor how fast a person falls asleep and what sleep stages they experience. The person doing the test has to nap five times in the day, with each nap separated by two hours.

Questions to Ask

These questions will help you start a conversation with your doctor about how to best manage your narcolepsy.

About Symptoms

- ❑ Do I have sleep paralysis and hallucinations because of narcolepsy?
- ❑ Are any of my symptoms unusual for narcolepsy? Could another condition be causing them?

About Causes & Risk Factors

- ❑ Are there any known risk factors that contribute to the development of narcolepsy?
- ❑ Do you think an autoimmune disease is contributing to my specific case?

About Diagnosis

- ❑ Should I monitor my sleep and symptoms in a journal?
- ❑ Should I have a sleep study?

About Treatment

- ❑ What types of medications are available?
- ❑ What are the side effects of medication?
- ❑ Is it possible to control my narcolepsy with lifestyle changes alone?

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About Coping

- ❑ How do I maintain my work and social life while I figure out what treatment works best for me?
- ❑ Are there narcolepsy support groups?

About Living With Narcolepsy

- ❑ Do I have to give up driving and other activities that require full alertness, even after I start treatment?
- ❑ What other activities should I avoid while I get my condition under control?
- ❑ Are there any programs designed to help people with this specific disability maintain a normal life?
- ❑ How do I speak to my employer about my diagnosis so that it doesn't affect my work?