

Julie's Narcolepsy FAQ

Typical questions and simple responses

Q: *What is narcolepsy?*

A: Narcolepsy is a neurological disorder of the sleep/wake cycle.

Q: *So that's where you fall asleep all the time?*

A: Sleepiness is an aspect of narcolepsy, but it's a much more complicated disorder. The timing of my sleepiness is "off" – so I may fight sleep during the day but be unable to sleep at night.

Q: *Could you fall asleep right now?*

A: Probably not. I experience episodes of extreme sleepiness, but it's generally brought on by situations that would make anyone tired (like dark rooms, hot rooms, or jet-lag), but these situations make me 100 times more tired than normal.

Q: *What are symptoms of narcolepsy?*

A: Narcolepsy involves:

- Excessive Daytime Sleepiness,
- Cataplexy (muscle weakness with emotions),
- Hypnagogic hallucinations (vivid realistic dreams), and
- Sleep paralysis (inability to move upon falling asleep or waking).

Not everyone has all symptoms to the same degree.

Q: *Were you born with narcolepsy?*

A: No, people aren't born with narcolepsy. It usually develops in childhood, teens or early 20's.

Q: *How does narcolepsy develop?*

A: It's believed to be an autoimmune disorder in which brain cells called "hypocretin" deteriorate. Scientists are working on understanding this process.

Q: *I've never met anyone else with narcolepsy. Is it rare?*

A: Narcolepsy affects 1 in 2,000 people - about 200,000 Americans and 3 million people worldwide. Only 25% have proper diagnosed and treatment. Narcolepsy is often misdiagnosed as epilepsy, depression, or schizophrenia.

Q: *Is there treatment?*

A: I manage my symptoms by taking medication twice a day and twice a night. I also nap everyday. The best medications improve my symptoms, but make me sick in other ways. It's a give and take.

Q: *Does narcolepsy impact your life?*

A: Narcolepsy challenges me daily. Studies suggest narcolepsy affects quality of life comparable to epilepsy and Parkinson's disease. Undiagnosed, narcolepsy presents major safety concerns, compromises education, employment, and personal relations.

Q: *Is there a cure?*

There is currently no cure, but scientists are working towards better solutions, so hopefully someday!

Created by **Julie Flygare, JD:**

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