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),
• Hypnogogic 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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