



Narcolepsy Perspectives - A Closer Look: Katy's Symptoms

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This post contains mentions of sexual assault. National Sexual Assault Helpline: 1-800-656-4673

November 27, 2023 - Welcome back to Narcolepsy Perspectives: A blog about anything & everything Narcolepsy!

Back in September, Wake Up Narcolepsy launched the new blog series in celebration of World Narcolepsy Day 2023. Our [first edition](#) gave you a quick look into the lives of some of our community members, but we want to share a closer look!

This edition is all about Katy Scruton and her experiences leading up to getting diagnosed. You may remember Katy from our [World Narcolepsy Day edition](#) where she described a day in her life and how Narcolepsy was a constant balance.

People often wonder how to recognize Narcolepsy and it's important to remember that it can look different for everyone. Here's a bit more about what it looked like for Katy.

"All of the symptoms became overwhelming. It was hard to adjust from being a healthy individual with no health issues to experiencing full-blown hallucinations, encounters with the paranormal and uncontrollable sleep attacks. I felt mentally ill and drained of energy."

Katy, a freshman in college at the time, was experiencing many symptoms of Narcolepsy, such as [cataplexy](#), [hypnagogic & hypnopompic hallucinations](#) and [sleep paralysis](#), but didn't know what they were. Instead, she was surrounded by the unknown.

"I remember...

...walking across campus to a gymnastics class one day and being so tired I closed my eyes while walking down the sidewalk just because my body needed a nap so desperately.



...[I was a] lifeguard one summer and a local resident handed a newborn baby to me to hold while she greeted her children who were swimming in the pool. Thankfully I was sitting down, but the baby was so cute that my arm muscles gave out momentarily and the muscles in my neck failed to hold up my head. It was very brief and thankfully I didn't drop the baby because I was sitting down, but it was confusing and I summed it up to fatigue from being in the heat all day.

... laughing so hard while walking down the stairs in my dorm room that I went tumbling from the top of the stairs to the bottom [because of muscle weakness].

... sometimes I would get excited or laugh and my muscles would give out in the middle of a [cheerleading] stunt. At football games, I had to be careful not to laugh too much, but sometimes that happened when a partner would whisper something funny into my ear while out on the field and I would fall to the ground. One time [I was] so embarrassed because the medics ran over to me but I had laughed myself into complete paralysis and couldn't explain what was going on.

...I was visited by demons every night and thought that my dorm room was haunted. [Hallucinations] would also happen when I become drowsy and I thought I was seeing ghosts.

...Old hags would sit on my chest and suffocate me, demons, aliens, you name it.

...The worst part was when I started being sexually assaulted by these evil demons during my sleep paralysis episodes. It felt so real, with all five senses intact, so I started videoing myself to prove it wasn't actually happening.

"I later realized after finding a handwritten journal from my childhood, that my symptoms had started as early as age twelve after having the chickenpox. I was fortunate enough to receive an accurate diagnosis roughly four months after the full onset of symptoms, but in reality, six years from when the initial symptoms began."



Reducing the delay in diagnosis time is a key part of Wake Up Narcolepsy's mission and something that requires raising awareness. In order to reduce the stigma associated with Narcolepsy, we must listen to the voices of people who have it when they tell their stories.

Spreading education about the symptoms of Narcolepsy makes it easier for people to receive a diagnosis. If you want to learn more about the symptoms mentioned by Katy in her story, click on the links above or visit our [What Does That Mean? page](#) where we break down terms associated with Narcolepsy to make them easier to understand.

We'll leave you with some advice from Katy for those who suspect they have Narcolepsy.

"It is crucial to heed your body's signals and not ignore them. Take the initiative to consult a sleep specialist, educate yourself about the condition, and become an advocate for your own well-being. Empowering yourself with knowledge and seeking support can make a significant difference in managing and understanding this challenging condition."