Narcolepsy

By Fred Truck

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The Sleep Patient

Narcolepsy is a chronic sleep disorder characterized by overwhelming daytime drowsiness and sudden attacks of sleep. People with narcolepsy often find it difficult to stay awake for long periods of time, regardless of the circumstances. Narcolepsy can cause serious disruptions in your daily routine.

Sometimes, narcolepsy can be accompanied by a sudden loss of muscle tone (cataplexy) that leads to weakness and loss of muscle control. Cataplexy is often triggered by a strong emotion, most commonly laughter.

Narcolepsy is a chronic condition for which there's no cure. However, medications and lifestyle changes can help you manage the symptoms.

-- The Mayo Clinic

I have found it very difficult to think or write objectively about my narcolepsy. This condition is not something like a sore throat which appears, and you treat with medication, and then it goes away. I am writing this now at the age of 78. I was undiagnosed until I was 68. That means I was not aware of the disease for 87% of my life, up until this point. This doesn't mean that others—my family, my friends, acquaintances—that others weren't aware.

Many thought I was rude, or uninterested in them when I fell asleep at family dinners or holiday celebrations. It happened frequently enough that everyone in the family began to wonder, but no one made any connections.

Everyone who has narcolepsy has stories of sleep attacks. They aren't entertaining to those who experience them because these stories represent disruptions in everyday life. They are disruptions to overcome.

For example, I co-founded the Art Com Electronic Network in 1986. It was a network aimed at artists and getting them comfortable with telecommunications. The Network was based in San Francisco. As I live in the Midwest, meetings like this meant a long flight there, and another one to get back home. One time at a board meeting, I experienced a

very strong sleep attack. It hit me so hard I collapsed and banged my head on the table.

Later some board members wondered if I was epileptic. Not that I know of—was all I could say. And it was true. I didn't know.

Hallucinations and vivid dreams

Many people with narcolepsy have dream-like hallucinations just as they are falling asleep or waking up. (Hallucinations when falling asleep are known as hypnagogic; when waking up, hypnagogic; when waking as a sense of a threatening stranger or dangerous animal in the room. Upon waking, it can take a few minutes to shake off the fear and appreciate that it was just a hallucination. Most likely, these hallucinations are rapid-eye-movement (REM) sleep-like dreams occurring when an individual is only half-awake.

Similarly, many people with narcolepsy have very vivid and intense dreams and nightmares while sleeping. In fact, some dreams are so lifelike that it can be hard to tell them from reality. For young children with narcolepsy, differentiating vivid dreams from reality can be especially difficult.

@http://healthysleep.med.harvard.edu/narcolepsy/

I began my creative career as a writer. I realized early on that I couldn't write without being able to see my subject. What I mean by "seeing" is very similar to eidetic imagery. I found that being able to see what I wanted to write about also generated the emotions that added depth to my subject.

I've always had intense dreams. A perceptive high school teacher suggested I write these dreams down, to see if any patterns appeared. I did so from about 1964 to 1974. It turned out that I had no repeating dreams, but I did have repeating images. Generally, I can say that even if they were surreal, and not all were, the surreal happenings went on in a hyper-realistic environment like a Magritte painting. Visual perspective was acute. Space was rationalized.

As I continued developing as an artist though I never stopped writing my work became more and more visual.

Inevitably as time went on my wife, Lorna, became more and more concerned about my erratic sleeping. At first, Lorna thought I was sleep deprived. I have no doubt that I was sleep deprived, but somehow, no matter how much I slept, or how well, I never seemed to catch up.

One day, Lorna said she thought I was narcoleptic. I resisted this diagnosis vigorously at first...but eventually, I decided to check it out without telling Lorna or anyone else what I was secretly about. The description of the narcoleptic experience fit me to a tee, but I didn't accept it. That just couldn't be it.

Then, I took the Epworth Sleepiness Test. The version I took was set up for narcolepsy. Out of a possible 24 points, I scored 21. Soon after that, I was diagnosed by a physician. I take Nuvigil, a medication that floods my brain with dopamine. My quality of life is much improved. Nuvigil has taken the edge off any sleep attacks I might experience but I still have dreams and intense visions.

A dream from a few nights ago:

I was in a strange house. I was living near the top story which was connected to all the other floors by a narrow spiral staircase. Apparently, there was no elevator. I was looking for my brother-in-law, Bob. I knew he lived in this same building. I went down the staircase. I knocked on a door, and Bob was there. I turned around to leave, then I turned around to say something else, and Bob was gone. I went down to the next floor and knocked on the first door I saw. Bob let me in, we chatted for a while, just as before, I turned around to go but had something else to say and Bob disappeared. Out in the hallway, I looked up

through the flights of stairs. I saw Bob on the top floor looking down at me. I woke up.

Narcolepsy has been a gift for me. I have had a difficult time adjusting but what wonders I've seen.