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Paralyzed

Paralyzed. She laid there, eyes scanning our faces frantically back and forth as no words could escape her mouth and no means of bodily movement possible. This was the first time our family ever experienced such terror as we watched our mother in such a state unfamiliar to us, a state of being that neither she nor us had any control over. Having never seen our mother in a condition as she was, fear dominated the room and we tried anything possible to wake her out of her paralyzed state. A slap in the face? No response. Shaking her back and forth rapidly while begging her to talk to us? No response. No matter what my stepdad, brother, and I tried, my mom was not moving or responding back to us, except through her eyes that appeared to be screaming for help.

Before I go on any further about this peculiar situation, let us back track a little in time to introduce my mother, the woman before her life was drastically changed. Cindy Carchia, formerly known as Cindy Skomin, and even further formerly known as Cindy Parenteau, is one of the strongest women I have encountered in my life. After divorcing my father, my single mother fought to keep her children healthy and happy. Although we lived in a tiny house for quite some time and did not get to spend as much time with her, we understood that she was always out working to support us. Most coworkers would describe her as the toughest woman at Brinks; a single mother, armed, driving a huge truck filled with money and boxes, and lifting these heavy loads from place to place. Not to mention, my mother had, and just about still has, the biggest attitude and most honest mouth for someone who stands only five feet tall. If you defy her or she does not like you, believe me, you will know it.

Now fast forward a little bit more in time, after my mother married my stepdad, graduated from Lincoln Technical School, and moved us to Smithfield, Rhode Island in a beautiful house in an even more beautiful, peaceful neighborhood. Cindy no longer had to slave away at Brinks, but instead, because of the education she chased after, she was hired at Epoch Sleep Center. My mother was at the time, and still to this present day, a sleep technologist at the center working third shift, studying patients as they slept in order to conclude whether or not they had sleep apnea or other sleep disorders, and to what degree or extent of sleep problems the patient had.

Keeping her occupation in mind, let's jump back to this peculiar situation where my mother randomly fell paralyzed for a reason unknown to us at the time. After several minutes of pacing back and forth, not knowing whether to call an ambulance or wait a little while longer, my mother suddenly "unfroze." She stood up, dumbfounded at what just happened, but knew exactly what it was because of her occupation. This was definitely the scariest moment in our lives, and it continued to happen every here and there, when my mother was in a state of high emotion, such as anger, laughing too hard, and becoming too upset. After months of hospital visits, fear, and tests, my mother finally concluded what was wrong with her before her own doctors did—a sleep disorder.

Ironic right? A person who spends a majority of their time studying others with sleep apnea and disorders while she, too, has one of the most serious, rare sleep conditions known—narcolepsy (NA) with cataplexy. The narcoleptic aspect of her condition is "characterized primarily by persistent and excessive daytime sleepiness (EDS), which is usually the first symptom to appear" (Utley 3). An individual with the disorder typically spends a majority of their sleep in a prolonged stage of rapid eye movement (REM), also known as the "dream stage," which prevents the person from getting a sufficient night of rest even if they slept enough hours. There are six symptoms of narcolepsy including EDS, although some of the symptoms may be mistaken for other health problems as they are common among individuals who do not have the disorder. After witnessing my mother experience all of the symptoms and understanding the dangers or consequences that may arise from the disorder, I found it imperative to spread awareness of the disorder and its common symptoms, as it is difficult to diagnose and unfamiliar to the general public and its knowledge of health disorders.

It may be common for some individuals without the disorder to experience the symptoms of narcolepsy at least once in their life, but most of the time, these symptoms classify the disorder and may be overlooked throughout one's lifetime. The only symptom that one will never get without the disorder, and that many people with narcolepsy may not even experience either, is cataplexy (cataplectic attacks). Unfortunately, my mother is one of the few individuals who experiences this symptom and it is the reason she becomes suddenly paralyzed after feeling strong emotions. It is defined as the "sudden, brief loss of muscle control, usually triggered by emotions such as laughter, anger, fear, or surprise, [a] feeling of weakness, limp/twitching muscles or total body collapse, [and] the inability to speak clearly if at all" (Utley 5) while the individual remains conscious. The other four symptoms of narcolepsy are hypnagogic hallucinations, sleep paralysis, automatic behavior, and lastly, disrupted nighttime sleep. Hypnagogic hallucinations are terrifying dreams that seem realistic when going to sleep or waking up, sleep paralysis is the paralysis of voluntary muscles when going to sleep or waking up, automatic behavior includes tasks that are performed without full awareness and may later be forgotten, and disrupted nighttime sleep involves many arousals during the nighttime period (Utley 5-6).

It seems as if narcolepsy is such a simple disorder that only interferes with an individual’s sleep, but it can be more serious than one thinks and has many consequences when overlooked or not diagnosed. Typically, early symptoms are uncommon, which leads to a postponed diagnosis, if the patient gets diagnosed at all. Throughout my life, I witnessed my mother constantly tired, yawning, falling asleep at family functions, and sleeping long periods of the day, even after a full night of sleep. Of course, her excessive sleepiness was overlooked by both my mother and our family, and was at times mistaken for her bipolar disorder because we figured she was in another state of depression and sleeping it off. It wasn’t until my mother aged and was in her mid-forties that her more serious symptom, the cataplectic attacks, occurred and she knew immediately what was wrong with her.

The *International Journal of Behavioral Medicine* states that, “Since a significant number of physicians, including family doctors, have little knowledge about the condition and do not have the resources to refer patients to sleep disorder specialists, early diagnosis and treatment of NA by physicians specializing in sleep disorders is unlikely. For this reason, a considerable number of NA cases are likely to be overlooked and untreated for a long period” (Ueki 966). A little while prior to my mother’s first cataplectic attack, we noticed her face was drooping to the left and she was acting strangely. She spent a significant amount of time at hospitals to speak with doctors and had multiple tests done to try and find a diagnosis, which they believed to be a stroke. The disrupted sleep from her narcolepsy began taking a toll on her body and energy, but nothing could be done until doctors had a final diagnosis on what her condition was. Although Cindy, my mother, is a sleep technologist and has knowledge of most sleep disorders and sleep apnea, she, too, overlooked the possibility of narcolepsy until she experienced her first cataplectic attack. At the moment the attack concluded, she was able to diagnosis herself because of her familiarity with the condition and the knowledge that cataplexy occurs only when an individual has the disorder.

If my mother didn't specialize in sleep apnea and disorders, her diagnosis may have been further postponed, leading to dangerous situations. The medication prescribed to her prevents the likeliness that a cataplectic attack may occur, which provides a great amount of relief for our family. The fact that my mother could have been driving down the road one evening, laughing at a conversation over the phone and suddenly go paralyzed is a very terrifying thought; both her life and the lives of others were constantly at risk before she was diagnosed. Also, "if left untreated, NA can lead to academic underachievement or job loss because of dozing off or mistakes caused by inattentiveness due to sleepiness. Undoubtedly, such consequences have a serious impact on quality of life" (Ueki 966). It is imperative that more doctors, family physicians, and the general public become more aware of rare, serious disorders such as narcolepsy because a diagnosis may draw the line between having a life of quality and enjoyment, or a life of constant, threatening situations and risks for both the individual and those surrounding them.

It is understood that a person with narcolepsy and cataplexy suffers greatly on a day-to-day basis if both untreated and treated, but many do not realize that the patient's family is also impacted by the stress that comes along with such a serious disorder. It was a relief to finally find out what was wrong with my mother, and an even greater relief knowing that there is a treatment for cataplexy. Xyrem, "oral sodium oxybate solution, is a valuable first-line option for the treatment of narcolepsy" (Lyseng-Williamson 282). I consider this medication to be a lifesaver; it put an end to my mother’s cataplectic attacks, for the most part, and relieved my constant worry of the possibility that my mom had an attack while driving or in a location other than the safety of our home. This medication works by “improving the continuity of night-time sleep, increasing stage 3 and 4 sleep, improving sleep latency and reducing the frequency of sleep onset REM periods (SOREMPs)” (Lyseng-Williamson 283); therefore, the cataplectic attacks and excessive daytime sleepiness are mediated while the quality of sleep is improved.

It is acceptable to assume that our lives are average again, without the worries and pressure of situations we were constantly placed in, all because my mother takes this medication every time she goes to bed and no longer has attacks. This is not the case, though, because even the medication itself has caused panic among our family. The first time my mother took Xyrem, I happened to be leaving school and walking back home to see how she was doing with her first dose of the medicine. Could you imagine my reaction when I stepped through the door, only to hear my mother acting crazy while my stepfather and brother were following her around the house, trying to calm her down? My mother’s body was not accustomed to the Xyrem, especially because it is a very strong, serious drug that is only for narcoleptic patients. “As sodium oxybate is rapidly absorbed and swiftly induces sleep, patients should take the medication after getting into bed and should lie down immediately after administration. It should be administered at least 2 h[ours] after food, as food significantly reduces the bioavailability of the drug” (Lyseng-Williamson 283). Well, my mom could not immediately lay down after her first dose because her mind and body reacted to the unfamiliar solution in its system.

Crawling around on the floor, laughing and barking at all of us, to suddenly being overcome with anger, to sorrow, to happiness, my mother could not control her emotions. It was an exhausting battle for my family as we remained patient with her, our only goal in mind being to get her back in bed for her first session of sleep on the medication. Words cannot explain this astonishing experience of watching my mom have no control over her actions. To me, it was almost as if my stepfather, brother, and I were the adults, “babysitting” a young child of about three to four years old; forcing my mother to sleep when her mind was telling her otherwise was as difficult as putting a child to sleep when they desire to keep playing.

At such a young age, I had a major responsibility of monitoring a whole other person, knowing that I could not even support myself without aid from my parents. My mother could not be left alone at home before her treatment due to the risk of a cataplectic attack, and always needed somebody around during her treatment. For the first few days of starting the new medication, we had to deal with this same challenge of getting her into bed while her emotions altered sporadically. Once her body adapted to the medication, my mother fell asleep quickly and effortlessly, another great relief for our family. After that, it was my turn to accustom myself to my mother’s new sleeping habits. Being a freshman in high school, there was a great amount of pressure already placed upon myself, ranging from schoolwork to newer responsibilities, such as exploring careers. Teenagers are unlikely to admit that they still need support and assistance from their parents, though they still have this privilege. This advantage became limited for me because of my mother’s condition, a very challenging consequence for somebody my age.

Due to working “third shift,” my mother’s free time was already limited to a certain degree; as a consequence, the time I have to see and spend time with her was significantly decreased even before her diagnosis. After she was diagnosed and began taking Xyrem, I had no choice but to adapt to more independence and doing many other activities without her help. “In patients diagnosed with narcolepsy with cataplexy, recommended lifestyle modifications include regular nocturnal sleep and attention to sleep hygiene, taking planned daytime naps, and making career choices that avoid possible hazards caused by narcolepsy" (Robinson and Keating 351). My mother's career choice best suited her condition as she typically slept long periods during the day and stayed awake at unreasonable times during the night. Her "regular nocturnal sleep" became the daytime, while our family maintained the average sleep schedule of staying active during the day and sleeping throughout the night. Once my mother takes her dose of Xyrem before bed in the morning, she cannot be woken up until the medication leaves her system, which is typically after the recommended duration of sleep. Our schedules are reversed; when I need my mother during the day, I cannot wake her up and must deal with the issue on my own or wait until the evening.

"Narcolepsy profoundly affects quality of life, reducing social activities, increasing the likelihood of educational/occupational failure and increasing the risk of driving and other accidents" (Robinson and Keating 350-351). It is difficult to witness my mother's quality of life impacted negatively due to a condition out of her control, but with the help of those who support her, my mom is able to remain optimistic. This disorder affects our family in ways many cannot understand without experiencing the stress themselves. The fact that narcolepsy is hereditary and could one day be diagnosed in my brother or myself makes the condition just as frightening and serious for our family; I can only hope that others become aware of the impact disorders have on both a person and their loved ones.

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