

LIVING WITH NARCOLEPSY AND CATAPLEXY

I'm Katelyn. I'm 34 and about 1.5 years ago my life was flipped upside down. I knew for years something wasn't right but I was always under the impression it was due to a sore neck. I had a funny head drop that was so minor no one ever said anything. I had absolutely no clue that my head drop would lead me to an unknown world.

I began experiencing full on cataplexy out of nowhere. I began falling to the floor and becoming paralysed. I couldn't open my eyes or breathe but I could hear and feel everything. This terrifies me.

The previous 3 years I was in and out of doctors complaining that I was so tired as soon as I woke up in the morning. I would be so sleepy at work that I would micro sleep in the middle of conversations. It got so bad that I could only work a 5-6 hours day. At this point, I had sooo many changes and things going on in my life that people perceived my extreme sleepiness as stress. I guess I was talked out of knowing in my gut that I wasn't ok. Things eventually got next level worse and I knew I had to find help. Through friends and family, I was lucky enough to find someone with a good amount of knowledge on narcolepsy. I was so extremely stressed that I began having cataplexy episodes for what I felt was nothing. Things like being asked if I was okay would take me out in a split second.

For those that don't know cataplexy is a sudden loss of muscle tone while a person is awake that leads to weakness and a loss of voluntary muscle control. It is often triggered by sudden, strong emotions such as laughter, fear, anger, stress, or excitement.

I had a Multiple Sleep Latency Test (MSLT) done and two weeks later I was called in for confirmation and a plan to begin life with narcolepsy.

Everything happened so fast that I didn't have a chance to take it in. To learn who I was or who I am now.

I began medication and unfortunately it triggered cataplexy. The episodes were for such a long time. Times where I couldn't breathe was so scary. I honestly felt like I was dying.

I tried to lean on my support network. I'm so very lucky that my friends and family are amazing in every way. No matter what though, I didn't and still don't feel understood. I feel compared to so many other conditions. Narcolepsy is so very hard to take in. For me though cataplexy is next level. It's unpredictable, it's like it controls your mind. I get it from all kinds of emotion. Depending on each one I will almost always have a different episode to go with it. The only way I have been able to cope is by isolating myself. Having people around me causes me to have cataplexy. No matter the kind of catch up. People don't understand how to help me or deal with it and I have absolutely no idea. I feel like I'm risking things by socialising. Most of my relationships have become distant due to me just not being able to

sustain conversations or keep up with messaging. I fall asleep looking at my phone. I have cataplexy in person. I've noticed if I'm laughing with people the funny stops because the cataplexy starts and doesn't stop. I feel like I shut down other people's personalities.

Mind power is everything with narcolepsy however I have lost the ability to use it. I can't function enough to have a normal routine. To do things that I need to so that I can live normally. I can't eat properly or sleep well at night. I forget almost everything. I have no sense of time and I feel completely lost.

Being taken into a dark world and told to live with it isn't easy. I don't feel like I have many options except to stay on my own. I have a dog that I have been working close with to help me at home. He's very alert to cataplexy and sleep attacks. I have learned to listen to him and I feel like he's onto it before it happens. Bentley has given me so much patience and time. He fulfills my lonely times. I honestly feel better with him around. I find daily life extremely hard now. Financially trying to pay for things and work to provide the income I need has become a battle. My weekly bills and the cost of medication is incredibly hard to swallow. It's all so much to understand and I'm spoken to like I'm supposed to know.

My journey so far is pretty terrifying and hard to take in. I really wish for a better understanding and more research into cataplexy. And more support for people who are diagnosed with narcolepsy and cataplexy instead of just expecting us to know how to just live with it.

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