

April 27, 2021

I live in a small, appealing village of about twelve hundred residents, surrounded by farms and forests. My family has been very content living here for many years.

I have life-long epilepsy and migralepsy. Medications don't control my condition, so I learned to manage my epilepsy by adapting my life habits and adjusting to carefully avoid anything known to cause my seizures. Over time it became second nature, and I was healthy, happy, employed, independent, and nearly seizure-free for decades.

Seven or so years ago, however, I had my first encounter with an LED light. It triggered one of the worst, most violent seizures I'd ever experienced. I didn't even know what LEDs were back then. Since then I've found that almost every version of LEDs provokes that kind of instantaneous reflex seizure, and other LEDs cause migraines which lead to seizures. It's a matter of minutes or of a split second, but one or the other happens every time I can't avoid LED lights. In the brief moment I have to see before my brain reacts, the worst LEDs look like a spray of strobing needles.

Suddenly LEDs were turning up everywhere, impossible to avoid, It was getting harder and harder to manage or go about my normal life. Then in late December 2019, streetlights throughout our village were converted to LEDs. I'd alerted our mayor and trustees several times by then to my disability and the danger inescapable LEDs are for me. Over eighteen months the mayor reassured me that they wouldn't vote for any public lighting that they knew would harm me. False reassurance, as it turned out. They went ahead and did exactly that, saying afterwards that yes, they knew LEDs would hurt me, but I was just one person and they'd decided that financial advantage for the village was more important. The village got lower utility bills and a cash incentive, and in exchange I was thrust into the very crisis I'd tried to prevent.

From that night on, I suffered hundreds of breakthrough seizures, constant blinding headaches and migraines, repeated physical injuries and a whole array of after and side effects. I couldn't set foot out the door or even look out the windows when the lights were on. Sometimes I had seizures inside our house if LED light got around cracks in the shades. I was increasingly incapacitated, and after four months the threat was so severe I was forced to flee our home and community. I've been in temporary quarters on a dear friend's farm ever since. I'm deeply grateful to have a safe spot to sleep on, but I'm separated from my family and heartsick from wanting to go home.

Neither the Village Trustees nor the utility company will make any effective accommodations for me, despite their actions being directly responsible for this devastation of my health and home life. We've been shut out of their discussions at every turn, and they won't communicate with us. They ignore everything we, my doctors, other village residents or The Epilepsy Foundation sends them. The mayor and trustees say they are "done" with the issue and have "zero desire" to help us. Our utility company, National Grid, just keeps referring us back to the mayor and trustees. It's as if my previous happy, healthy, free, contributory life never existed. I'm exhausted, terrified, and traumatized, and it seems that no-one who could help rectify this injustice cares to get involved.

My family and I are desperately trying to be heard. Not even the local police chief cares, calling it a matter for the mayor to address. I'm cut off from everything. I've lost thousands of dollars in wages and incurred thousands more in medical bills. Awful incidents keep happening: I broke a tooth during an epileptic seizure that first terrible month. (An angry dentist, when asked to use different lighting, threw down her tools and stormed off announcing "I can't work like this!" Her office called me later,

said I was a “difficult” patient and told me to go somewhere else.) The tooth is still broken, and I have an abscess now, but I can't find a dentist who will repair it without using LEDs. Then three months ago I had a nasty accident, after dusk, out where I go to stay each night. I couldn't get to emergency treatment because the urgent care center and nearest hospital are surrounded by LEDs. Badly injured and in severe pain, I couldn't even try to recover at home - because of the LED street lights. I can't go shopping, can't get to or from work, can't use thruway rest rooms, can't walk up to take-out windows, can't be home for Hannukah candles, and can't take an evening stroll. I nearly had a seizure getting a COVID vaccine because the tent in the parking lot had LEDs on - in a tent, in the daytime! LEDs make a barrier I can't cross. Encountering one - inside or out - is like being cracked on the head with a brick.

This has been my life for sixteen months and counting. Ten days ago, National Grid finally swapped five LED bulbs back to the previous HPS bulbs in streetlights beside our home. We're on a corner in the middle of the village and the very next ring of LED streetlights reaches our house. It's useless. As a friend from the synagogue said, “Oh great! Now you can stand up and turn around in your cage!” I might be marginally safer *in* the house. Maybe I could peek out of a window now, but a solution it's not. The mayor and trustees make it clear that five swapped lights are all I'll ever get, *and* the HPS bulbs will go straight back to LED after they burn out. Two of the five trustees (the mayor and deputy mayor) actually voted against even making even that tiny change. It did, however, demonstrate that LEDs can indeed be taken out and replaced, and the streets won't descend into darkness and chaos.

I think of the other people with LED-light-sensitivity around the country, living their own version of this nightmare with the same staggering stress and fear for the future. Lately it's an effort for me to think about any different topic for any length of time. I read the paper, but good news seems to have nothing to do with me; bad news just compounds the misery. Either way, I'm not the engaged, productive person I was and no help now to anyone anyway, not even my own family. I'm trapped in a state of shock and don't recognize myself anymore. And all because of a *light bulb*. A light bulb!