

FIRST PERSON

I LIVE WITH EPILEPSY AND ALL ITS GLORIOUS FACETS



ILLUSTRATION BY DREW SHANNON

Epilepsia is the name I've given my female companion who represents the duality in me. She's the one who transcends time and space, **Mo Duffy Cobb** writes

In 2018, my husband and I went to Tulum. What I had remembered as a dusty strip 20 years ago has now become a world-class destination, but looking back in time churned up a lot of memories. Living with epilepsy, I have always existed in a neuro-atypical space, one of neurons and charges, galvanized energy and, as my childhood neurologist described them, "lightning storms in the brain."

Thinking about my seizures sometimes spills over into sleep. *I dream I'm in a tent, I've had a seizure, and I am panicked.* I will be startled awake, scared. What if my dream was a vision, a warning? Am I unconsciously tapped into something in the complex elliptical circuitry of the universe? Although about 50 million people globally are affected by the condition, epilepsy is still, however, the domain of the hushed, the misunderstood, the mythologized.

For me, the condition is genetic. My father and his siblings fondly recount their brother, Charlie. Born in the 1940s, he never went to school, had daily seizures and was remembered for wearing a hockey helmet until his untimely death at the age of 12. Luckily, we've moved on with better treatment options, but this is the legacy I have inherited.

Children with epilepsy still fumble around in the dark. A psychologist friend asked me to speak to one of her clients – a 10-year-old with epilepsy – whispering, "she thinks she's the only one who has it."

I know those feelings well: isolation and fear. My epilepsy started out as an absence seizure, a complication. Then I moved into the teenage angst of seeing my friends get their driver's licenses. By then, it was generalized – or grand mal – seizures and a program of medication.

"Do you see ghosts?" the 10-year-old asked.

"Absolutely," I answered. "At least, that's what it feels like." Few know this, but there is a constellation of illusory phenomena that is common with epilepsy. Most of it relates to misfires in the brain, déjà vu and vague familiarities, but the young mind bends and turns under these impressions. Seeing ghosts seems the closest we have to describing it, signalling an alarming deficit in the English language. Growing up, I was convinced I was psychic. I dreamt about people before I met them. I found lost objects. I tweaked a keen sense of intuition, meditated on astral travel and kept vivid dream journals. I became obsessed with clairvoyance and the paranormal. I began to read tarot. I wondered, "Was epilepsy my superpower?"

Most of the time, people see only what epilepsy takes away – your dignity. While seizures leave limbs flying, difficulty breathing and a bitten tongue, the postictal state brings its own state of altered consciousness, causing drowsiness and amnesia. I've had seizures on bikes, in cars and in countries where I don't speak the language. I've woken up everywhere from hospitals to ditches. One time, I even rode my bike half a mile through traffic before a friend saw me riding erratically and took me home. But even after biking unconscious into traffic, I am still alive.

In Tulum, I stare out at the sea. I. Am. Still. Alive. Epilepsia is the name I've given my female companion who represents the duality in me. She's the one who stops the clocks, who transcends time and space. She's the flirt, the temptress, the expert conversationalist. She's the one who hates to leave the party. I'm the stern sober one, keeping myself away from bright

lights, booze and long bouts of sleepless nights under flashing house beats, the places that would induce a lapse in consciousness.

Epilepsia has not been without her gifts. She sent me a mother who protected and prayed for me when I didn't call, when I hitchhiked through the night. Mom begged me not to travel alone, but Dad said simply, "It's your life." Sometimes even a wild mare has to learn.

Epilepsia also sent me two older brothers, caretakers who managed my 10-year binge of poetry and partying, who gave me curfews and put alarms on my phone to take my meds. "You need to sleep, Mo," they would say, over and over. But I was stubborn and years away from learning the word "no." I refused to live within the confines of the word, epilepsy.

Eventually, I embraced the fact that I was a walking nuclear reaction, full of hydrogen atoms and stardust and fire. I began to understand that, somehow, I belonged to a spirit world, especially after reading Anne Fadiman's book, *The Spirit Catches You and You Fall Down*, the title is a translation of the word epilepsy in the Hmong language. In the Hmong culture, most epileptics grow up to be shamans. One time, I thought that was me; I was born to be a shaman.

Epilepsia sent me a sweet husband, who has always quipped that he had to hold on to me by my coattails or I would float off into the stratosphere. It's true that I was always set to drift.

And perhaps before I was ready, epilepsy conjured a baby girl – whom I dreamt of before she was born – who was so perfect and timely that she signalled an end to my roaring juvenescence. The drowsiness of pregnancy stabilized me into a quiet that my molecular makeup had never known, and for eight years, epilepsy left.

"Are you scared you might have another seizure?" The young girl asks.

"I sure am," I say. "But it's okay to be scared sometimes. You have to be really brave to live with epilepsy." Fierce bravery, creativity and uniqueness are all equal trade-ins for a neuro-atypical existence.

Recalibrated after our Mexican holiday, my husband and I entered the Cancun airport to a long line of travellers. A man at the counter has fallen, and my husband quickly shields me when I see he is having a seizure. Briefly, I wonder if I caused it.

We land in Montreal and begin the long walk to the gate for our connecting flight. When I wake up, I am on a stretcher, in a Montreal airport broom closet, and the flight is gone. Time has passed, and my consciousness has travelled somewhere with it. When I get home, it is time to rebuild.

For now, I have reached equilibrium again, including the practicalities of doctor consults, medication adjustments and finding a comfortable space where the spiritual meets the physical.

Although I sometimes feel I teeter on this astral intersection, I don't resist an early bedtime any more, nor do I keep my condition a shameful secret. I explain, I educate. Even to my students or my kids, who may not necessarily get the full severity of what "Mom has."

Hopefully, some day there will be a cultural shift in the conversation, and I will pave a way for the ones who will come after me, like my 10-year-old friend. Or, I suppose, it's never too late to be a shaman.

Mo Duffy Cobb lives in Charlottetown.

First Person is a daily personal piece submitted by readers

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TODAY'S SUDOKU SOLUTION

5	2	4	7	8	3	6	9	1
9	8	3	2	1	6	5	7	4
1	7	6	9	5	4	3	2	8
3	4	1	8	2	7	9	6	5
6	5	7	4	3	9	1	8	2
8	9	2	1	6	5	4	3	7
7	3	8	5	9	1	2	4	6
4	1	9	6	7	2	8	5	3
2	6	5	3	4	8	7	1	9

TODAY'S KENKEN SOLUTION

6+	3	3-	144x	5-	
5	3	2	4	1	6
1	2	5	6	4	3
3÷	2	1	4	3	30x
6	7+	4	3	2	5
15x	3	5	6	1	30x
4	5-	1	5	3	2

The 2021 movie season is finally heating up – unless you're in Canada

JOHANNA SCHNELLER

OPINION



For the first time in Oscar history, there are diverse nominees in each of the Big Eight categories. If you're in Canada, however, you probably haven't had a chance to see several of the films. And it's unclear when you will.

The best picture nomination for *Judas and the Black Messiah* is the first for an all-Black producing team. For the first time, two women are nominated in the same year for best director – Emerald Fennell for *Promising Young Woman*, and Chloe Zhao for *Nomadland*. In the best actor category, three of the five nominees are men of colour, and one of them, Riz Ahmed (*Sound of Metal*), is also the first Muslim best actor nominee. Two Black women – Viola Davis (*Ma Rainey's Black Bottom*) and Andra Day (*The United States vs. Billie Holiday*) – share a best actress nomination, the first time that's happened since 1973. And the supporting actor, supporting actress and two screenplay categories also include diverse nominees.

The high number of nominees of colour may be a silver lining of the COVID-19 shutdowns. Hollywood delayed most of its 2020 wide releases, waiting for theatres to reopen. This allowed more attention to fall onto intimate, lower-budget films – which tend to feature protagonists and storylines outside the mainstream – that could have been steamrolled in a regular year.

Many of the nominated films arrived via streaming and video-on-demand (VOD) services, which removed the pressure to equate quality with box-office success. People stuck at home may have taken a chance on fare they might not have driven to a cinema to see, and audiences outside urban centres, without arthouse cinemas, had access to movies they normally wouldn't have.

Unless you're north of the 49th parallel, that is. For all kinds of reasons – the entangling of rights to competing streaming services; theatrical distribution deals; and especially the fact that many cinemas in Canada simply aren't open – we are still waiting our turn to see some of the top titles.

For example, *The Father* – director Florian Zeller's delicately harrowing view from inside the mind of a man (Anthony Hopkins) losing ground to Alzheimer's, based on Zeller's own play – is nominated for six Oscars, including best picture, adapted screenplay, actor (Hopkins) and supporting actress (Olivia Colman, playing Hopkins's dutiful daughter). It's scheduled to open in theatres on March 19 – in whatever patchwork of theatres are open – and on-demand March 26.

Nomadland is in a similar bind. Widely considered the front-runner for best picture and best actress (Frances McDormand), and nominated for four other awards, it's now open in U.S. cinemas and available on the streamer Hulu, which Canadians don't get. Disney-owned Searchlight was hoping to open it in Toronto cinemas on March 19, and other select theatres across Canada on April 9. But Canadians who want to see it as of April 9 will probably have to sign on to Star, the new add-on of the streamer Disney+.

This is the dark cloud around that silver lining. Arthouse distributors and streamers embraced home viewing for their Oscar titles, knowing they weren't likely to be monster box-office hits. (Oscar films rarely are, even in a normal year.) But a new blockbuster season is right around the corner. Will Canadians be cut out of it?

The United States is far ahead of Canada in COVID-19 vaccinations, and their theatres are reopening much more quickly. (Half of California's residents were able to return to movie-going as of Tuesday, albeit at 25-per-cent capacity.) So by May, U.S. audiences could well be munching cinema popcorn and thrilling to Marvel's *Black Widow*, starring Scarlett Johansson; *Cruella*, the Swinging Sixties-set backstory of the Dalmatian-clad Disney villainess, starring Emma Stone; and *A Quiet Place Part II*, John Krasinski's follow-up to his alien-invasion jump-fest.

Meanwhile, we in Canada probably will be stuck in a much, well, quieter place. What if our theatres are still dark? Will Paramount, Disney and the other studios be willing to forgo big box-office returns and make those titles available here if we can only watch them at home?

Warner Bros. may have its answer. To date, the studio has sent its theatrical titles, which are also HBO Max titles – including *Wonder Woman 1984*, *Judas and the Black Messiah*, *Tom and Jerry* and *The Little Things* – to premium-priced VOD here in Canada, where we have neither many open theatres, at least in such major markets as Toronto and Vancouver, nor HBO Max.

But that sound you hear is the thundering tread of the studio's big spring title, *Godzilla vs. Kong*, due out March 31. It boasts a diverse cast, including Brian Tyree Henry, Eliza Gonzalez, Shun Oguri, Demián Bichir and Ronny Chieng, although it likely won't earn them any Oscar love. With a budget of US\$200-million, it is not intimate; indeed, it's a monster – a pair of monsters – a steamroller, a juggernaut and a tsunami rolled into one. And here in Canada, we will watch it in theatres only, whenever the real monster, the pandemic, allows.