

Behind the wheel: Navigating driving with epilepsy

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Jessica Veach didn't wait long enough at the stop sign.

"You got too excited," the instructor told her, writing a large "X" over



her driving test. Veach, who was retaking the test after having <u>epilepsy</u> <u>surgery</u>, failed because of her rolling stop. She cried afterward.

"I'm 30," she said. "And I'm failing."

For people with epilepsy, the ability to drive ranks among their top concerns. Regulations vary among countries; many have some restrictions on driving for people with epilepsy, but some have no policies. In many areas—particularly rural ones—driving restrictions can limit independence and hamper the ability to get and keep a job, pursue higher education, and transport children to school or activities.

Effect on people and decisions

Veach, executive director of the Epilepsy Foundation Mountain West Region, lives in the United States. In her state of Washington, people with epilepsy must be <u>seizure</u> free for at least six months before they can drive. Physicians are not required to report to licensing authorities in the state, but Veach said that her doctor recommended she stop driving until she was seizure free.

"It was just frustrating," she said. "You're counting down the clock, going along, and then you have another seizure, and you have to start over."

Veach passed her <u>driving test</u> the second time and was able to reinstate her license.

"It's just part of the epilepsy journey, and I was fortunate," she said.

Veach said the inability to drive can cause daily frustration and boredom. People with epilepsy already feel isolated from stigma, she said, and driving restrictions can feel like a punishment.



Sonika Kainth has epilepsy and is currently opting out of driving, due to changes in her medications. In Canada, people with epilepsy must be seizure free for six months before they can drive.

Kainth, a Toronto-based physician, said that her city offers transportation options that suburban or <u>rural areas</u> do not. For example, she can walk to some <u>grocery stores</u> or take <u>public transit</u> to work.

"Even though sometimes it's frustrating, at least I don't have to rely on somebody else," she said. "I can still live my life."

Kainth and her partner are planning to move out of the city and are prioritizing public transportation. Accessible transit and a workplace close to home are important to Kainth; she has already turned down a job offer due to its location.

Varying regulations and relative risk

Restrictions on driving with epilepsy vary widely between countries and regions. Some regulations require seizure-free periods as short as three months, while other nations, such as China and India, impose lifetime bans after a single seizure.

Vinay Jani, who has epilepsy and lives in Delhi, said that the ban is not always enforced.

"In metropolitan [areas], the law is strict," he said. "But if I go to smaller cities, things are lenient."

A 2023 study surveying people with epilepsy in eastern China found that about 42% of participants were aware of the driving restriction there. But roughly the same percentage drove a vehicle daily, and about 70% opposed the lifetime ban on driving.



This resistance is not only restricted to countries with lifetime bans. Germany bans driving in people with uncontrolled epilepsy, but a 2018 German study found that 15% of participants with uncontrolled epilepsy still drive on a regular basis. Drivers tended to be employed—either with permanent or freelance work—and live alone.

Jani said that while public transportation options in Delhi make the Indian driving regulations less frustrating, he does hope the law will change. He recently joined a driving task force started by a local epilepsy organization to help initiate further discussion.

Alejandro de Marinis, head of Neurology and Psychiatry at Clínica Alemana, Santiago, Chile, said that governments must find the right compromise so that people will be truthful about their seizure history and not lie in order to drive.

"You have to really find a way to take a reasonable risk," he said. "Like everything in life and medicine."

De Marinis noted that gathering data about driving and epilepsy poses some methodological issues, but that the risk of a person with epilepsy having an accident while driving is lower than many might think.

According to data compiled by the <u>Belgian Traffic Bureau</u> in 2001, the maximum relative risk of a traffic accident caused by a person with epilepsy is 1.8. This is a lower risk than that of many other demographics, including:

- Men younger than 25 (7.0)
- Women younger than 25 (3.2)
- People 76 and older (3.1)
- People with 17-19 hours of sleep deprivation (2.0)
- People with a blood alcohol content of 0.05% (2.0)



A 2020 publication also found that accident risk in people with controlled epilepsy is lower than that of other demographics. Researchers analyzed data from surveys sent to physicians and people with epilepsy across Japan. They calculated the relative risk of a traffic accident in someone with epilepsy seizure-free for at least one year at 1.22, with a relative risk for people seizure free for at least two years at 1.15. They compared these numbers with risks for several other groups:

• Men in their 20s: 1.71

• People 60 and older: 1.31

• People 65 and older: 1.52

• People 75 and older: 2.69

Data on the risks of driving with epilepsy vary dramatically. One Swedish study estimates that people with epilepsy have a 37% increased risk (relative risk 1.37) of serious transport accidents compared with the general population. A 2023 retrospective cohort study found that people with epilepsy are generally responsible for 0.1%–1% of all U.S. motor vehicle accidents annually.

However, these studies don't always compare the risk of people with epilepsy to the risk of other demographics, and some have limitations. For example, the Swedish study noted that none of its source registers included information about whether the people with epilepsy in the accidents were driving or were passengers, or if they were at fault.

Having a seizure while driving can, of course, be dangerous. Researchers from the U.S. and Germany used a <u>driving simulator</u> in an epilepsy monitoring unit to study associations between driving risk and seizure characteristics. They recorded 51 seizures in 30 people with epilepsy. <u>The study confirmed</u> that bilateral motor seizures and focal seizures with impaired awareness lead to driving impairment, while focal seizures without impaired awareness do not.



But a 2009 publication argues that most motor vehicle accidents involving people with epilepsy are due to driver error, not seizures. In the general population, driver error causes 85% of all motor vehicle accidents. And scholars argue that the percentage of accidents caused by people with epilepsy is lower than the 7% estimated to be caused by alcohol abuse.

"In a society that is used to people consuming alcohol, they might find these accidents, this mortality, as natural somehow," de Marinis said. "I think there is also sometimes bias or discrimination."

John Dunne, professor of Medicine at the University of Western Australia, believes that driving is a privilege, not a right, but that people with epilepsy should be evaluated fairly.

"The idea that a life ban is going to create a safer world for people on the road or near the road is incorrect," he said.

Evaluating fitness to drive and physician relations

So how do countries determine fitness to drive in people with epilepsy? Historically, regulations have been based on expert opinion rather than scientific evidence.

In some US states, driving authorities require physicians to report people with epilepsy. Many argue that mandated reporting places doctors in a difficult position and may make them liable for any accidents.

A Canadian study found that adults with epilepsy in Ontario and Alberta had similar lifetime accident rates to one another. Ontario has mandated physician reporting for people with epilepsy; Alberta does not. Both groups also had similar lifetime accident rates to a control group of people without epilepsy. However, 20% of drivers with epilepsy were



unlicensed in Ontario, compared with 9% in Alberta.

The authors concluded, "Although it is clearly dangerous for many people with ongoing seizures to drive, the findings provide no support for the hypothesis that mandatory reporting of patients by physicians reduces accident risk and suggest that concerns about the impact of epilepsy on driving compared to other medical and nonmedical risk factors may be excessive."

A seizure-free period of six months to a year is strongly associated with reduced risk; one study found that people who had a seizure-free period of at least six months reduced their risk of accidents by 85%; a seizure-free period of at least 12 months reduced risk by 93%. Still, individual risk can vary. Dunne advocates for reasonable conversations between doctors and their patients that allow them to make the best decision while preserving a trusting relationship.

"There has to be a situation where the doctor treating the patient isn't the person who's going to take their license away," he said. "The doctor is making the person as safe as possible... We can't control everything, but we can partner with our patients to guide them best."

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