

Driven

to Raise Awareness

Recent developments in treating epilepsy are welcome news for many, including NASCAR competitor Matt Tifft, who has spoken publicly about his seizure disorder. BY STACEY COLINO

Ever since he was a kid, Matt Tifft has loved to race vehicles. In 2007, at age 11, he raced a go-kart. Four years later he graduated to stock cars, and in 2013 he competed in his first NASCAR event. For a man whose passion and livelihood involve getting behind the wheel of a car, developing a seizure disorder is particularly devastating.

After his first seizure in October 2019 at the track and a second one two months later, Tifft was diagnosed with epilepsy in January 2020. So far he's had seven seizures, the longest of which lasted four minutes. According

to the laws of North Carolina, where he lives, Tifft must be seizure free for at least six months before he can drive *any* vehicle. Not only does that mean no racing, it also means relying on friends or rideshare services to get to work or run errands. "It's a lot to try to adjust to," says Tifft, co-owner of Live Fast Motorsports, a NASCAR cup racing team.

"For me, it was a big deal to go public," the 24-year-old says. "So many people have epilepsy but stay quiet about it. Seizures are scary, and epilepsy is an invisible disease—you can't see that someone has this until a seizure happens. If you have epilepsy, you should let people know so they

can help you stay accountable about taking your medication or help you if you need it. Everyone else should realize that people with epilepsy are still themselves. A seizure is just an electrical firestorm in the brain."

The cause of Tifft's epilepsy remains unclear. Initially doctors thought it was related to a benign brain tumor that was surgically removed in 2016, but that theory didn't bear out. Another possible cause was the six concussions he's had over the years. Epilepsy experts often don't know the cause but consider various risk factors, including concussion. What did become clear to Tifft and his doctors, after he underwent an electroencephalogram (EEG), which



Matt Tifft was a promising NASCAR driver when a diagnosis of epilepsy sidelined his racing career.

detects electrical activity in the brain, was that Tiff's seizures originate deep inside his brain and spread from there.

Before a seizure, Tiff typically experiences a 10- to 15-second aura that feels like a mild electrical charge on his tongue. Then his eyes roll upward, his legs shake, and he becomes rigid before passing out. "The worst part is the unpredictability," says Tiff, who got married in December 2019. "The physical pain is one thing; the mental health part is a bigger deal. I had several months where I was afraid to leave the house." After the highest dose of one anticonvulsant drug failed to

control his seizures, Tiff switched to another and began taking medication to quell his anxiety. "Finding the right treatment is so hard—it's all trial and error, which is frustrating," he says.

Epilepsy, a neurologic condition characterized by abnormal electrical activity in the brain, affects one in 26 people in the United States, according to the Epilepsy Foundation. New cases of the disorder most commonly appear in young children and older adults but can develop at any age.

Amy Mittinger had her first seizure in 2005 when she was 15 and a sophomore in high school. "Out of the clear blue,

I felt like I was in another dimension. Nothing felt real," says Mittinger, now 31 and a hospital administrator in Cleveland. "It was a subtle feeling. I was 100 percent functional and aware of where I was. But I felt like I was having an out-of-body experience." She was diagnosed with focal seizures, which start in one area of the brain and don't affect consciousness; the person remains alert and able to interact.

Over the next three years Mittinger tried seven different antiseizure medications, none of which controlled her seizures. In 2008 her doctors suggested temporal lobe surgery, an



Eight Ways to Manage Epilepsy

Epilepsy may be highly unpredictable, but there are habits people can adopt to improve their ability to manage it.

1 Stick to a medication schedule. "The number one reason for breakthrough seizures is missed doses of medication," says Sheryl R. Haut, MD, director of the adult epilepsy program at Montefiore Medical Center at Albert Einstein College of Medicine in the Bronx, NY. "Set an alarm or use a weekly pillbox to remind yourself to not miss a dose."

2 Don't mix drugs. For people with epilepsy, certain stimulants, antidepressants, antihistamines, and narcotics can increase their susceptibility to a seizure, says Rebecca E. Fasano, MD, associate professor of neurology in the epilepsy

division at the Emory University School of Medicine in Atlanta. Before using these medications, talk to your doctor and let him or her know you have epilepsy.

3 Identify your triggers. Keep a diary to record when and where your seizures occur and try to identify patterns. For example, if bright or flashing lights are triggers, avoid them. If you're susceptible to cluster seizures in high-risk situations, you may be able to take a rescue medication preventively, says Dr. Haut. Or your physician could prescribe an additional medication for short-term use. The Epilepsy Foundation offers a free tool called My Seizure Diary to help people track their seizures, recognize triggers, and manage medications.

4 Find the right diet. The basics of good eating—healthy, minimally processed foods like fruits, vegetables, whole grains, nuts, and lean proteins—apply to people with epilepsy as they do to everyone else. For some people with drug-resistant epilepsy, a ketogenic diet—which is high in "good" fats and protein and low in carbohydrates—or a modified Atkins diet (similar

to keto but less restrictive) helps control seizures, says Shawniqua Williams Roberson, MD, assistant professor of neurology and of biomedical engineering at Vanderbilt University in Nashville.

5 Sleep tight. For many people with epilepsy, insufficient sleep triggers seizures. One study, reported in *Epilepsy Research* in 2016, found that in the 24 hours before their seizures, people with epilepsy got an average of one hour less sleep than usual. Be sure to get the amount of sleep you need every night.

6 Drink less alcohol. Excessive drinking and the withdrawal that follows are highly risky, says Jacqueline French, MD, FAAN, chief medical officer of the Epilepsy Foundation. According to a 2018 issue of *Epilepsy Research*, while moderate alcohol intake wasn't a cause of seizures in a study's participants, even occasional binge drinking was associated with less seizure control.

7 Manage stress. A study in a 2016 issue of *Epilepsy & Behavior* found that people with uncontrolled epilepsy had

higher perceived stress levels and more sleep disturbances than those with well-controlled epilepsy. Exposure to high levels of stress results in the release of stress mediators—such as glucocorticoids and neuropeptides—throughout the brain, particularly into the hippocampus, a region that's especially prone to seizures, according to research in a 2017 issue of *Trends in Neurosciences*. To reduce the effects of stress, consider relaxation techniques such as progressive muscle relaxation (PMR), yoga, biofeedback, or deep breathing exercises. A 2019 study in *Current Opinion in Neurology* conducted by Dr. Haut and colleagues reviewed the research on behavioral interventions in epilepsy and found that mindfulness techniques and PMR were particularly beneficial in reducing seizure frequency.

8 Exercise regularly. The exercise-induced release of beta-endorphins and other substances may inhibit abnormal electrical activity in the brain. Plus, "exercise is important for general health, well-being, and mood," says Dr. French.



A week after his first seizure in 2019, Tifft addressed the media at a track in Texas about his condition.

option for patients whose seizures don't respond to medication, diet, or other therapies. The surgery removes the part of the temporal lobe that causes the seizures but does not affect functions such as speech, vision, hearing, or motor activity. The operation reduced Mittinger's seizures by 75 percent, she says. She still has about two mild seizures per month, even while taking four antiseizure medications.

The cause of epilepsy varies. It may be genetic (due to inherited or acquired gene changes), structural (related to a physical cause in the brain), metabolic (stemming from disruptions in the way the body uses food to make energy), autoimmune, or the result of brain trauma or an infection. "We used to look at epilepsy as a constellation of clinical signs," says Stephan Schuele, MD, FAAN, professor of neurology at the Northwestern University Feinberg School of Medicine in Chicago. "Considering the underlying cause is a different way of looking at the disease." But in many cases the cause remains unknown, as it does for Tifft and Mittinger.

Of the hundreds of forms of the condition, focal epilepsy and genetic generalized epilepsy are the most typical, says Jacqueline French, MD, FAAN, chief medical officer of the Epilepsy Foundation and professor of neurology at NYU Langone Health. In focal epilepsy, seizures start in one area of the brain and can lead to twitching,

jerking, or limp muscles, as well as nonmotor symptoms such as changes in sensations, thinking, or emotions. With generalized seizures, both sides of the brain are affected, and symptoms may include sustained rhythmic jerking movements; tense, rigid, limp, or weak muscles; and spasms. Patients may be unaware or lose consciousness, make unusual or garbled sounds, repeatedly blink their eyes, bite their tongues, or have trouble breathing.

Regardless of the specific symptoms, seizures can alter or disrupt the way messages are sent between brain cells and trigger changes in symptoms, sensations, or behavior. "I think of it as a huge pep rally where neurons send a surge of signals to other neurons and they send them back," says Shawniqua Williams Roberson, MD, assistant professor of neurology and of biomedical engineering at Vanderbilt University in Nashville.

The standard treatment for epilepsy is antiseizure medication, and there are different types. Some affect sodium or potassium channels, which mediate and conduct electrical impulses in the brain; others target neurotransmitter levels in ways that either enhance or inhibit electrical activity in the brain. All the drugs are designed to prevent the spread of excessive electrical activity through the brain or to raise the threshold at which a seizure is likely to occur, Dr. French says.

Many epilepsy drugs have side effects, which may include mood changes, dizziness, fatigue, and weight gain. Landing on the right drug means finding a medication that works well for the patient while avoiding intolerable side effects. "We don't have a way to predict which drug is going to work for a particular patient, so we usually have to try more than one," says Rebecca E. Fasano, MD, associate professor of neurology in the epilepsy division at Atlanta's Emory University School of Medicine.

Approximately one in three people with epilepsy has a treatment-resistant form; such people continue to have seizures even after they've been on two or more antiseizure drugs. Several new therapies that became available over the past few years focus on treatment-resistant epilepsy. Other developments in treating the condition range from nasal sprays to less invasive surgeries.

Newer Medications

In 2019 the US Food and Drug Administration (FDA) approved cenobamate (Xcopri) as an adjunctive therapy for treatment-resistant focal seizures in adults. According to a study published that year in *The Lancet Neurology*, cenobamate was associated with a significant reduction in seizures among that demographic.

Last summer the FDA approved the use of the cannabidiol medication Epidiolex for seizures associated



Tifft and his wife, Jordan, at his first Daytona 500 race, in 2018.

with tuberous sclerosis complex. It had already been approved for use in patients with Dravet syndrome and Lennox-Gastaut syndrome, rare forms of drug-resistant epilepsy that appear in childhood.

Valtoco and Nayzilam, two benzodiazepine nasal sprays, have been approved for the acute treatment of seizure clusters; both are considered rescue medications used to stop a seizure quickly and prevent it from escalating to a medical emergency. “The epilepsy community had been waiting for these for decades,” says Sheryl R. Haut, MD, director of the adult epilepsy program at Albert Einstein College of Medicine’s Montefiore Medical Center in the Bronx, NY. “Many patients experience seizures in clusters or acute repetitive seizures, which rescue medicines can interrupt.” Previously, they were treated with rectal suppositories of diazepam (the benzodiazepine in Valtoco).

“These nasal sprays are game changers,” says James W. Wheless, MD, FAAN, chair of pediatric neurology at the University of Tennessee Health Science Center in Memphis. “They can be given during a bout of seizures or used to interrupt a cluster of repeated seizures. They have empowered our patients and their families dramatically.” People who have consistent warning signs may be able to use the nasal spray to prevent seizures, he says.

Many drugs are also now available in extended-release form; taken orally once a day, they are slowly released into the bloodstream and stick around longer. “These forms are especially important for teenagers as they transition into young adults. Taking a pill once a day may fit their lifestyle better,” says Dr. Wheless.

Now that some genetic causes of

certain types of epilepsy have been discovered, patients may be able to undergo testing to identify the mutation and compensate for the consequences of it. For example, in Dravet syndrome, which doesn’t respond well to medication, a gene mutation that disrupts sodium channels in the brain is the most common cause of seizures. Scientists are studying whether it’s possible to introduce a genetic probe—a single strand of DNA—to increase productivity of one of the sodium channels. Many experts consider these gene therapies the wave of the future. “If we understand the functional changes in the brain that lead to seizures, we can potentially counter-regulate what has gone wrong,” says Dr. Schuele.

Surgeries have also progressed. Less invasive procedures such as laser ablation, which doesn’t require opening the skull, are now performed. Guided by an MRI, the surgeon inserts a small probe into the area where seizures originate and delivers heat to destroy the problematic tissue, Dr. Fasano explains. As reported in a 2020 issue of *Epilepsy Research*, in a study involving 60 people with various forms of drug-resistant epilepsy, 64 percent of the subjects who underwent laser ablation were seizure free a year later, and most of them were significantly less worried about seizures.

“We expect tremendous advances in ablating or removing tissue where seizures begin and curing the epilepsy or getting it to be responsive to medication,” Dr. Haut says.

Three different neurostimulation devices, implanted surgically, also can help some people with drug-resistant epilepsy. In responsive neurostimulation, electrodes are placed in the brain where seizures

begin, and an implanted device that records brain activity delivers electrical stimulation to prevent a seizure. With deep brain stimulation (DBS), which was initially approved for Parkinson’s disease, electrodes are placed in the thalamus, and a pacemaker-like device is implanted in the chest to signal the electrodes to stop activity that would provoke a seizure. The DBS system is programmed to deliver stimulation on a fixed cycle, independent of whatever brain activity is happening at the time. With vagus nerve stimulation for the treatment of focal epilepsy, a small stimulator device secured under the skin in the chest has a wire that attaches to the vagus nerve in the neck; the device sends regular electrical signals to the brain to try to reduce the number and severity of seizures.

Dr. Schuele predicts the development of additional brain stimulation devices, including ones that can identify seizure patterns and essentially defibrillate the brain, in the next few years. “The ability to modulate brain activity could be a promising tool in patients where the area of the seizure isn’t clear,” he says.

Mobile devices and watches also can track epilepsy. “A lot of people are unaware that they’re having seizures,” Dr. French says. New seizure-alerting apps for smartwatches and other wearable devices can track seizure symptoms over time and notify other people when a seizure occurs.

With so many options, people with epilepsy can customize and fine-tune their treatment, but self-care is another important part of managing the condition. For Mittinger, that means avoiding sugar, sleeping 10 hours a night, and staying physically active—she takes long, brisk walks, and before the pandemic played volleyball and softball regularly. “I feel okay, and I can manage,” she says.

Since his diagnosis, Tifft has shifted to a low-carbohydrate diet. He eats at regular intervals, stays well hydrated, and makes sure he gets at least eight hours of sleep each night. He also exercises consistently, with weightlifting and cardio workouts several times a week. His last seizure was his shortest and mildest. “I focus on what I can control, which is medication and my schedule,” he says. ■