

# Epilepsy and the social stigma surrounding it

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According to the World Health Organization, approximately 50 million people worldwide have epilepsy, making it one of the most common neurological diseases.

Epilepsy is a chronic disorder of the brain characterized by recurring seizures, which are brief episodes of involuntary movement of the body sometimes accompanied by loss of consciousness. The disorder spans all age groups, and to onlookers it can instill fear, misunderstanding and discrimination.

November is National Epilepsy Awareness Month. VCU News spoke with Victor Gonzalez-Montoya, M.D., co-medical director of the Epilepsy Monitoring Unit at VCU Medical Center to better understand the disorder. Gonzalez-Montoya is also an assistant professor in the Department of Neurology in the Virginia Commonwealth University School of Medicine.

## **What causes epilepsy and how can it be treated?**

Epilepsy is a disorder in the brain in which there are spontaneous episodes of uncontrolled and excessive electrical activity that often disrupt its function. It can be pretty dangerous.

There are multiple causes, like lesions in the brain due to an injury, tumors, strokes, infections, genetic conditions and others. Sometimes we can find the direct cause for epilepsy, and other times it's difficult.

But the way we diagnose and treat seizures has changed dramatically, thanks to research. The majority of time, we treat epilepsy with medication. If someone resists medication, they may seek treatment at a Level 4 Epilepsy Center, which is the highest level. VCU Medical Center is a Level 4 Epilepsy Center, and therefore we typically provide diagnostic and treatment techniques that are not widely available; techniques that help us localize the problem in the brain and see if a surgical procedure or brain stimulation is an option.

Surgery in the brain can scare people, but that too has come a long way.

If [surgery](#) is an option, there are different types, depending on the patient: epilepsy resective surgery, minimally invasive laser surgery, responsive neurostimulation and deep-brain stimulation. Every patient's brain is like a different universe, so we model the treatments to the patient.

## **How does epilepsy affect one's daily life?**

The disease is horrible. There are many variables that determine how a seizure affects the [brain](#), and that determines how it appears in someone's life. It could be anything from a twitch in one hand to someone losing complete consciousness, falling and having a convulsion that leads to injury.

If you have epilepsy, you don't know when any of these things will happen. So as a patient, you live under the assumption that at any given time you cannot function normally. There are plenty of activities a patient with epilepsy cannot do. For example, someone with epilepsy cannot drive. So if they don't have a good public transportation system nearby, they rely on someone to take them anywhere they need—like going to the market to get milk.

In many cases, epilepsy by itself is associated with depression, and all of these social limitations worsen the depression because they cannot take part in activities that the rest of us can. It's a perpetuation. Epilepsy has a 360-degree effect on someone's life.

## **What don't people understand about epilepsy?**

We don't realize it, but as a society, we demand a high level of functionality. We indirectly punish those with epilepsy, when in reality they need a lot of support—from their coworkers, family, friends and

the community.

Family impacts vary by culture. Some families are very hard on someone with epilepsy, which can lead to worsening of depression. Sometimes they're not allowed out of their houses. They may not be able to go on dates like their friends. There have been reports of people losing friends because of the social effects of their disorder.

At work, people sometimes won't tell their employers they have epilepsy. The law protects them, but since they don't have the same functionality as someone without epilepsy, they fear their employers may find another reason to fire them.

At school, epilepsy requires the teachers to be educated on the disorder. Really, patients become the teachers of their condition because they need to share with people the correct actions to take if there is a seizure.

## **Why do you think National Epilepsy Awareness Month is important?**

It is extremely important. This is a month that you have the chance to reach out to the community and say: Listen, wake up. If you know someone with [epilepsy](#), there are things you can do to change or improve how you interact with them. Let's have a conversation about it.

It's a good start in not only alleviating the stigma, but also sharing what to do and what not to do if you see someone having a seizure. At the end of the day, it is about improving the lives of those suffering from the disorder in every way we can.

Provided by Virginia Commonwealth University

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