

NEWS

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* * * * Social alienation is number one problem for those with epilepsy.

Note to the editor: November is Epilepsy Awareness Month.

DALLAS--Many victims of epilepsy receive a warning as a prelude to their seizures. One person smells lemons, another sees cartoons. Thirty-year-old Cindy hears voices--sometimes a weather report, sometimes her mother calling her name, even though her mother is hundreds of miles away.

These "auras," the first sign of abnormal electrical discharges in the brain, often allow time for the person to get to a safe place before a seizure.

Auras can also save some epilepsy victims the social embarrassment of having a seizure in public.

Related to head injury, infection, genetic malformation, tumor or a number of other causes, epilepsy is a buildup and discharge of many neurons in the brain. Seizures can happen to anyone. Yet in spite of the fact that approximately two million Americans have seizure disorders, social discrimination is often far more damaging than the disease itself. "Social alienation is usually the major problem these people must face," says Dr. Albert Ehle, associate professor of neurology at the University of Texas Southwestern Medical School and a specialist in the field of epilepsy.

Cindy, an attractive and pert mother of three, learned the hard way how insensitive people can be regarding epilepsy.

She had her first seizure nine years ago as a junior in college. Unlike others who experience seizures with muscle spasms and loss of consciousness, her symptoms involve mental confusion. She develops a type of "aphasia," a language disorder where she can understand what is said to her but when she speaks "the words come out sounding crazy," she says.

Her first seizure began late one night while Cindy was studying in her college dorm room with her roommate. She got up to walk across the room and quite suddenly she fell to the floor, hitting her head as she fell. Her roommate ran for help and an ambulance was called. When the paramedics arrived, one of them yelled in her face, accusing her of drug overdose. She was strapped to a stretcher and carried through the halls, lined with her schoolmates. One girl screamed.

As the ambulance rounded the first corner, the seizure ended and she was again able to speak coherently. Then, as if to punish her for the inconvenience she had caused, the driver pulled over to the side of the road and made her get out and walk back. Her peers greeted her with icy silence and her roommate felt too uncomfortable to ever talk to her about what had happened.

"The social stigma is the toughest thing to deal with," says Cindy. "You begin to understand the social implications when you begin to have seizures at people's cocktail parties. There just seems to be a lot of ignorance and resistance to learning about epilepsy."

Ehle points to the fact that eighty percent of people with epilepsy can be totally or almost totally freed from symptoms through medical therapy. And he says that medical therapy has improved in the last five years with the addition of two major drugs for seizure control--Valproate and Carbamazepine. "Scientists are developing newer drugs with fewer side effects--the primary side effect being intoxication. And we are now able to monitor actual levels of most drugs in the body," says Ehle.

But there are still many remaining mysteries regarding epilepsy, he says. "We know a lot about the events of a seizure itself. But we know much less than we'd like to on the fundamental question on why seizures begin in a given individual, and why after similar head injuries eighty percent of the people don't develop epilepsy while twenty percent do. We also know little about why a given seizure occurs when it does in a person who has a seizure disorder."

It is the unpredictability of the disease which is the most frightening aspect to deal with, he says. "Patients know that seizures can happen at any time. But for a large part what happens is out of their control. This can affect their basic personality."

Epileptic seizures can be mild or severe, but even the most severe usually last only a few minutes. Cindy believes that when she fights an oncoming seizure and becomes tense the seizure is worse than when she relaxes and puts her brain "in neutral." But individuals vary.

There are three main types of seizures:

"Generalized tonic-clonic"--in which nerve cells are involved throughout the brain. The seizure consists of a tonic phase in which the person becomes rigid, falls down and loses consciousness. Breathing becomes irregular and in some cases it may stop briefly. Then the clonic phase involves jerking movement of the muscles, clenching of teeth and general convulsions. Some people experience only one type of spasm, either tonic or clonic. This type seizure, which can occur at any age, usually lasts from one to several minutes.

"Generalized non-convulsive"--which is most common in children ages six through 14, also involves nerve cells throughout the brain. Typically the person has "blank spells" by losing awareness with slight twitching and staring or blinking. These attacks usually last only a few seconds and they may occur dozens or even hundreds of times a day. They are hard to recognize and the person may be mistaken for daydreaming.

"Partial"--in which abnormal activity occurs in only part of the brain. Occuring at any age, the form this seizure takes is determined by the function of the part of the brain that is involved. One common type of these seizures is characterized by a period of mental confusion followed by pointless movements (such as chewing or hand-rubbing). These seizures and their after effects may last up to twenty minutes and are occasionally mistaken for alcohol or drug abuse.

Less common types of seizures include a type which causes spasms in only one part of the body, without loss of consciousness, and infantile convulsions, in which babies lose consciousness or muscle control for a very brief time.

Living with the physical symptoms may be difficult. But living with people who lack understanding can be much worse. Jobs and many types of insurance may be hard to come by. And some states still have laws making it illegal for people with epilepsy to marry.

People with epilepsy often find help by calling local chapters of the Epilepsy Foundation of America, which offers counseling and information about low-cost medication, special group life insurance and support programs.

An active leader of her local EFA group, Cindy explains the social implications of epilepsy this way:

"People are the mirrors in which we see ourselves. With epilepsy you never know what kind of reaction you'll get from a person. When people look at me as a sick person or an unacceptable person I have to look away. I can't let them diminish me in my own eyes."

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