

Communicating About Epilepsy

Modern treatment enables many people with epilepsy (seizure disorders) to lead normal lives. But age-old fears and prejudices continue to cause social problems that too often severely limit their participation and personal fulfillment.

So many misconceptions surround epilepsy that communicators may inadvertently add to the negative image of the disorder merely by choice of language. The following is an effort to call attention to usage of terms that in some manner communicate a negative image of epilepsy.

Disease

Many people with epilepsy prefer the term *disorder*, since the condition is not a disease in the usual sense of the term—it is a disorder characterized by a recurring disturbance in the electrical activity of the brain. To the general public, the term *disease* has connotations of being unsightly, progressive and contagious. Epilepsy and seizure disorder(s) are equally acceptable terms that may be used interchangeably.

Epileptic

Like all individuals with disabilities, people with epilepsy dislike labels, such as in “He’s an epileptic.” This dislike can be summed up by the statement, “epilepsy is what I have, not what I am.” The preferred terminology is *person with epilepsy* or *child with epilepsy*, rather than *epileptic*, which can be cumbersome for headlines, something that is, in fact, rarely an issue (see *Stereotyping* below). Use of *epileptic* as an adjective, as in “epileptic seizures” is appropriate.

Fit

Although the term *fit* is commonly used by the medical profession in the English-speaking world outside of the U.S., most individuals with epilepsy in the U.S. are particularly sensitive to the description of seizures as *fits*. The feeling is that this word connotes mental derangement or loss of emotional control. Some associate the word with the symptoms of rabies in animals. *Seizures* or, in some cases, *convulsions*, is preferred. (*Convulsion* is a more specific term that more aptly describes a single type of seizure involving muscle contractions throughout the entire body. Not all epileptic seizures are convulsions. Some seizures may amount to only a momentary stare.

Control

Seizures are controlled with medication, persons with epilepsy are not. “Controlled epileptic” is particularly to be avoided as it often gives the impression that the person needs to be restrained from willful, aggressive behavior. The adjective *violent* as a description of

a seizure is also unfortunate because the term implies a threat to others and a force out of control. Actually, there is no danger to anyone from the seizure.

Stereotyping

In the past, stereotyping has created unfounded associations between epilepsy and crime or violence, and between epilepsy and mental incompetence. “Epileptic Charged in Murder” makes as much sense as “Insomniac Charged in Murder,” yet this type of headline is not uncommon.

Persistent Myth

Perhaps the most persistent myth is that people having seizures can swallow their tongues. It is not physically possible to swallow your tongue. The tongue, if relaxed, could possibly block the airway. The way to avoid this is to turn the person on her side so the tongue falls away to the side of the mouth.

Lifesaving Acts

Sometimes news of dramatic lifesaving acts on the part of passers-by merely perpetuate the myths surrounding epilepsy first aid. Stories about people who save a life by keeping the person with epilepsy from swallowing his tongue are not only inaccurate, but also damaging. They produce a whole new set of misinformed people. Similarly, mouth-to-mouth resuscitation is hardly ever needed in connection with a seizure. Breathing is naturally depressed until the seizure ends, when it usually begins again without assistance.

Lesser Seizures

All seizures are serious. Absence seizures (formerly known as *petit mal*) may seem less severe than generalized tonic-clonic seizures (formerly known as *grand mal*), but they're not. Although tonic-clonic seizures (or convulsions) are more dramatic and expose the person experiencing them to serious injury, a child who has 50–75 absence seizures an hour may suffer more severe consequences from them—such as a severe functional disability—than a person who has two or three tonic-clonic seizures a year. The parents of the child who has almost debilitating absence seizures will likely—and rightfully—take exception to their child's condition being referred to a lesser form of epilepsy.

For More Information...

For more information, please contact the Epilepsy Foundation's national office at 301-459-3700, or Office of Public Relations, Epilepsy Foundation, 8301 Professional Place, Landover, MD 20785. You can also visit our Web site at www.epilepsyfoundation.org.