

## Living with Epilepsy

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Introduction. Any chronic medical condition makes life more complicated and epilepsy is no exception. People with epilepsy often have to live with the possibility of sudden, unpredictable interruptions of their activities. They may have memory loss or even become injured as a result. A number of techniques are available to help maintain control over one's life and treatment. Many people use lists or organizers to keep track of every day activities. MedicAlert bracelets and/or a written set of instructions kept in a wallet or purse will help insure that one's wishes regarding his or her medical treatment are carried out, even if unconscious or confused. It is extremely important that a list of current medications, dosages, allergies, and other essential medical information be easily accessible to medical personnel. Friends, family, and coworkers should all be aware of the condition and how to respond to a seizure including if and when to call for help. These techniques can help restore a sense of control to an otherwise frustrating and sometimes frightening situation. In addition to these general issues, epilepsy has implications for other major activities.

Driving. In this country, driving is the key to functional independence and most of us take the privilege for granted. For those with epilepsy, however, the ability to drive is a major concern. Not being allowed to drive

for any reason has a major impact on one's life and is especially disruptive to employment. It is certainly justifiable to restrict the licenses of those who are having frequent seizures and are at high risk for losing control behind the wheel. A seizure while driving can have tragic consequences. Deciding when or for how long to restrict those with less frequent attacks or even after a single seizure is more controversial.

All states regulate the driving privileges of people with episodes of loss of consciousness and those laws vary from state to state. Most states establish a minimal period of seizure freedom required to obtain or reactivate a license. This period ranges from 3 months to 2 years and may be modified with a doctor's recommendation. This corresponds to the American Academy of Neurology Quality Standards Committee analysis. After a thorough review of the literature, they concluded that there was an insignificant difference in accidents prevented by a 6-month driving ban as opposed to a 12-month ban. However, they recognized that individual situations may vary and that some flexibility may be needed while recommending further evaluation of varied restriction periods and the circumstances affecting the decision.

A few states, including Colorado, allow the patient's physician to determine the appropriate restriction rather than mandating



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a specific period of time. The patients are required to abide by that recommendation. Restrictions are generally based on the best statistical evidence of when someone is safe to drive and take into account the patient's previous seizure frequency, but there is unfortunately no way to be absolutely certain that the patient will remain seizure free. Some states also require physicians to report anyone who has a seizure to the Bureau of Motor Vehicles. Colorado does not require routine reporting, but a physician may report a patient if he or she discovers that the patient is not following the appropriate driving restriction and feels that the patient is putting himself or others at risk by continuing to drive. In most states, patients can appeal their driving restriction to a medical advisory board.<sup>4</sup>

Other countries tend to be even less lenient. In 1996, members of the International League Against Epilepsy (ILAE) met in Brussels and adopted the European Principles regarding assessment of fitness to drive.<sup>1</sup> They made recommendations based on whether the event was a single seizure or whether the patient had epilepsy, whether or not there was an underlying neurological disorder and made more strict recommendations in the case of commercial licenses. However, each country has adopted its own standards. Most require a 1 to 2 year driving ban.<sup>2</sup>

*Employment and Insurance.* For a patient with seizures, employment can be a challenge. Even after a single seizure, returning to certain occupations is nearly impossible. For example, a pilot must be seizure free for 10 years before he or she is eligible to reapply for a pilot's license. Jobs which involve driving, operating heavy equipment, working in or around water or at

heights are not recommended for people with epilepsy for obvious reasons.<sup>3</sup> Even with those challenges, most people with epilepsy are gainfully employed, although not always in jobs that fully maximize their potential. Creative solutions are sometimes needed to insure the safety of the patient and coworkers especially if the patient tends to wander while in the postictal period of confusion.

Obtaining insurance can be a problem with any chronic medical condition. If there is a group policy offered by the employer, a patient must be offered coverage in spite of pre-existing medical illness, although covered services vary from policy to policy. However, because of the problems finding and maintaining appropriate work situation, many people with epilepsy are without health insurance. Many have to turn to Medicaid or Medicare. Even if they qualify, these programs often do not adequately cover sophisticated testing and treatment. Lack of access to newer and effective, but often more expensive treatment can lead to a vicious cycle of more seizures, injuries, and more intractable epilepsy as the years go on. Those who do not qualify and do not have health insurance through their jobs, or who are unable to keep a job because of seizures, have even fewer options. Outside of employer-sponsored plans, people with epilepsy frequently cannot obtain life insurance coverage.

Automobile insurance can also be difficult to obtain. An assigned-risk insurance pool is available in about 25 states, but the cost is higher than an average insurance policy. If a patient decides to drive against medical advice while restricted, the auto insurance policy may not cover claims incurred during that time. This is a major risk that most people with epilepsy are unaware of.

Sports. Physical activity is important for everyone. Epilepsy poses special risks to those who wish to participate in certain sporting events. For contact sports, sudden unawareness can leave them completely unprepared for impact and can lead to injury. If reasonably well controlled, most people can participate. People with extremely frequent seizures, however, should not participate in contact sports and anyone with the disorder should voluntarily refrain from these activities if experiencing auras or other symptoms, which tend to precede seizures.<sup>5</sup>

A seizure while swimming carries the obvious risk of drowning, not only to the patient, but also to anyone trying to rescue someone who is thrashing and confused. No one with seizures should ever swim alone. People with epilepsy should always swim with others around, preferably with a lifeguard in the vicinity. Supervised camps with specially trained lifeguards or volunteers are a good way to indulge in this activity.<sup>6</sup>

Depression. Depression is a significant problem for people with epilepsy as it is with other neurologic conditions, such as Parkinson's disease. The prevalence of depression in epilepsy is as high as 65 percent. If the depression becomes chronic, it is sometimes called interictal dysphoric disorder. Symptoms include sadness, irritability, and loss of interest or pleasure in normal activities.<sup>7</sup>

At some point during their lives, most people with epilepsy will experience depressive symptoms, which are severe enough and last long enough to warrant treatment. Some antiepileptic medications also function as mood stabilizers and may control both problems.<sup>7</sup> However, most people with both conditions will need antidepressants for some period of time and

some need long-term treatment. Usually, patients respond well to drug therapy. Occasionally, psychiatric intervention is needed for severe depression, other mood problems, or even psychotic symptoms. Treating these comorbid conditions appropriately is as important to quality of life as controlling seizures and should not be neglected as part of the overall care of the patient with epilepsy.

Conclusion. There are many adjustments that someone with a chronic illness needs to make. The symptoms of epilepsy with episodic loss of awareness and potential for injury require planning and resilience that can take the spontaneity out of life. By being aware of the possible problems, planning ahead, being vigilant about changes in mood or attitude that might indicate a growing depression, and taking early steps to address these issues, life can still be full of joy and adventure.

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