

EPILEPSY *and the Family*

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A New Guide



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This book is meant to educate, but it should not be used as a substitute for personal medical advice. Readers should consult their physicians for specific information concerning their individual medical conditions. The author has done his best to ensure that the information presented here is accurate up to the time of publication. However, as research and development are ongoing, it is possible that new findings may supersede some of the data presented here.

This book contains many references to actual cases the author has encountered over the years. However, names and other identifying characteristics have been changed to protect the privacy of those involved.

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Chapter One

Epilepsy: Its Characteristics and Impact

Patrick was interested in a career in medicine because his father had epilepsy. Although the seizures frightened him at first, he quickly learned how to help his father when an attack occurred. Rather than running about excitedly and calling for help, he would safeguard his father, piling pillows around him and moving objects that might injure the convulsing man. He would advise friends and relatives what to do and what not to do during attacks. If young children were present, he would reassure them that the seizure was frightening but not dangerous. His father admitted that he relied heavily upon his son, and that without Patrick's keen sense of when a seizure was about to occur he would have suffered many more injuries than he did. Patrick was 3 years old at the time.

Miriam's young son, David, had had seizures since birth and had undergone several operations to treat birth defects associated with the epilepsy. Even with his mother's constant attention, David had as many as fifteen seizures a day. Miriam was obsessed with the dangers that he faced every time he had

a seizure. Her husband understood her preoccupation with David and spent all his spare time helping with his supervision and medications. Even so, the child took up all of Miriam's time and attention. Their four other children had to look after themselves.

Elizabeth married a man who had his first seizure a few days before the wedding. The epilepsy soon became intractable despite a variety of medications and other less conventional treatments. Elizabeth's every action had to take her husband's seizure disorder into account. Her thorough preoccupation with it became clear when she went to renew her driver's license. Looking at the form she had filled out, the clerk asked her to answer additional questions about her epilepsy. After a moment of confusion she realized that she had indicated on the form that she suffered from epilepsy. Even after the error was pointed out to her, Elizabeth felt that her answer was quite accurate: her husband's seizures were as much an impairment for her as for him.

Epilepsy is a tendency to have recurrent seizures. Seizures are episodes of disorganized electrical activity in the brain that can produce a broad spectrum of signs and symptoms, ranging from involuntary movements to loss of consciousness (see Table 1). Like any chronic medical problem, epilepsy affects not only the person suffering from it but also that person's family. Parents whose children develop epilepsy must cope with special restrictions, constant medications, and perhaps learning or behavior disorders. Other children in the family may be deprived of their fair share of attention because of the extra demands of the child with seizures. A wife may find that after her husband develops epilepsy he can no longer support the family or loses interest in sex. Alternatively, for some people with epilepsy, seizures are fully controlled with medications and minor adjustments to lifestyle. Whether the impact of the seizure disorder is highly intrusive or minimally disruptive to any family is often determined as much by the

TABLE 1
Characteristics of Seizures and Epilepsy

Seizures	Epilepsy
Caused by inappropriate electrical activity in the brain	Characterized by recurrent seizures or a neurologic syndrome associated with seizures
Neurologic signs and symptoms are transient	Seizures occur with little or no provocation
Altered consciousness, involuntary movements, and disturbed perceptions often occur	One or multiple seizure types may occur, and seizures may change with age
Defined by neurologic signs and symptoms and EEG patterns	Defined by spectrum of seizure types, EEG patterns, and clinical setting

family’s techniques for dealing with the disorder as by the volatility of the disorder itself.

The impact of epilepsy on a particular family is partly determined by the type and frequency of the seizures. Even well-controlled epilepsy, in which the affected person hardly ever has a seizure, can be very disruptive. The threat of seizures, even when seizures have been under control for many years, can inhibit the activities of the individual and the family. That a family member has a seizure disorder remains a major consideration in the family’s plans and activities. Parents may obsessively shelter their affected child. The husband of a woman who has only occasional seizures may doubt that she can be relied upon in a crisis. The entire family may treat the person with epilepsy as “sick” even decades after the last seizure has occurred.

If the seizures are poorly controlled and the affected person

has frequent and unpredictable seizures, they can destabilize the family and drain its financial and emotional resources. Circumstances thought to precipitate seizures take on an almost magical significance, and the family will go to great lengths to avoid them. If social activities seem to bring on a young girl's seizures, her parents may isolate her from friends. A couple may decide not to have a second child because the wife had more frequent seizures during her first pregnancy. Many families fear that any change in lifestyle or routine, however slight, may trigger a new round of seizures. Family interactions can become desperately rigid and oppressive. The person with seizures may be surrounded by tension even if all members of the family insist that the epilepsy is not a significant problem.

In the final analysis, the goal for every person with epilepsy is to lead as normal a life as possible. Ideally this is a life without seizures; if that cannot be achieved, it is at least a life free of unreasonable fears or prohibitions. The family helps to determine what kind of life the person with epilepsy will live. Lowered expectations can become self-fulfilling prophecies. An adult who is expected to take little responsibility within the family because of a seizure disorder often lives up to that expectation. An overprotected child will grow up to be an unprepared adult. A person who has always been treated as "sick" will have trouble realizing her own capabilities. In fact, most people with seizures are able to lead largely normal lives. Informed and understanding families are vitally important in helping them do so.

Characteristics of Epilepsy

Epilepsy occurs in men, women, and children of every culture and nationality. In the United States it affects at least one out of every two hundred people. It is a disturbance of the electrical activity of the brain that can abruptly interfere with behavior, perception, movement, consciousness, or other brain

functions. Individual attacks of disorganized electrical activity are called seizures; when attacks occur repeatedly, the problem is called a seizure disorder or epilepsy. Because of the stigma attached to the term epilepsy, some physicians avoid using it. Patients may be told instead that they have seizures, fits, brain attacks, convulsions, drop attacks, or other problems that do not include the terms epilepsy or epileptic.

The term “convulsion” is usually reserved for seizures in which jerking of the limbs or trunk and loss of consciousness are prominent features. Seizures are so often referred to as convulsions that physicians routinely call medications to suppress seizures “anticonvulsants,” but a more accurate term is antiepileptic medications. It is a bit misleading to call antiepileptic medications anticonvulsants, since these medications are used for all types of seizures, not just for convulsions.

Inappropriate, disorganized, or excessive electrical activity in the brain is believed to be the common element in all seizure disorders. Different types of seizures may have little else in common besides this electrical dysfunction. Nerve cells in the brain communicate and regulate one another’s activities primarily by way of electrical signals running along fine extensions from the body of one nerve cell, or neuron, to other neurons (Figure 1). Seizures occur when this electrical activity runs amok and the exchange between nerve cells becomes chaotic. Seizures seem to be an especially likely consequence of this electrical chaos when the nerve cells in the most superficial layers of the brain are involved. Coordinated or at least somewhat disciplined activity in this part of the brain is essential for normal consciousness, sensation, strength, and movement. During a seizure, one or all of these brain functions may be affected to varying degrees.

In some types of epilepsy, seizures cause loss of consciousness, whereas in others, consciousness is minimally impaired if at all. Some types of seizures invariably include involuntary movement and hallucinations, and others never produce ab-

normal movements or changes in vision, hearing, smell, taste, or other sensations. Although there are many different types of epilepsy, most people with seizure disorders experience only one type of seizure.

Misconceptions and misunderstandings develop at least in part because epilepsy is not a single entity with simple characteristics, and seizures are not a single phenomenon with stereotypical features. Carl, a businessman who developed seizures after a head injury, insisted for several years that he did not have epilepsy because his episodes of altered consciousness involved wandering, peculiar movements and behavior,

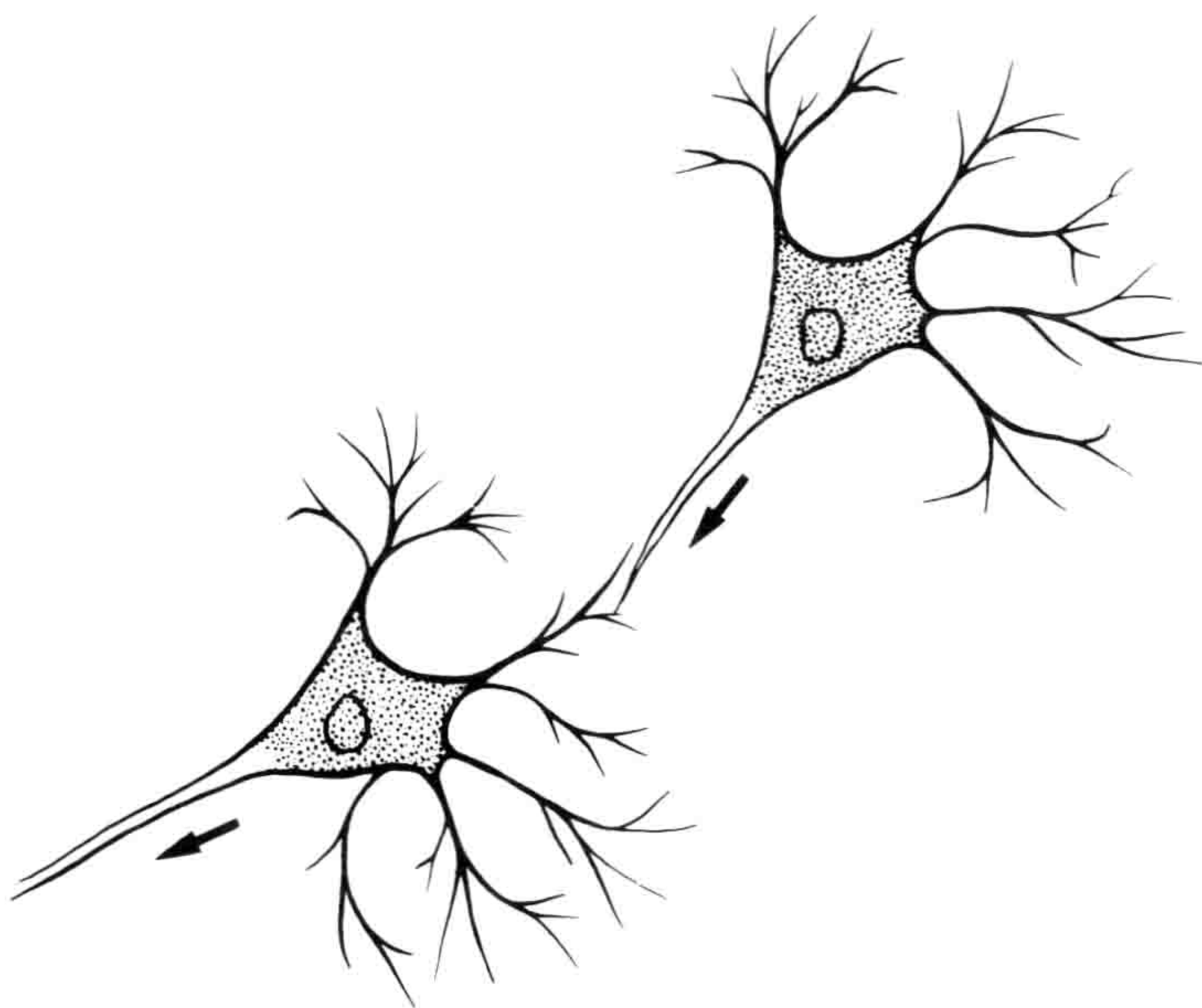


FIGURE 1. Schematic drawing of nerve cells (neurons). Electrical signals travel along projections (dendrites and axons) to and from nerve cells to transmit information from one part of the brain to another. The brain has billions of cells forming complex circuits. The message traveling from one cell to another may either inhibit or excite the nerve cell receiving the signal.

and temporary loss of memory but no jerking of his arms or legs. He insisted that a person with epilepsy always lost consciousness, fell down, and had convulsive movements of the limbs. What Carl recognized as epilepsy—and what many nonmedical people consider to be epilepsy—is a generalized tonic-clonic, or so-called grand mal, seizure. The type of seizure he was experiencing is a partial seizure with complex symptoms, also known as a complex partial or psychomotor seizure. This common misconception about seizures and epilepsy allowed Carl to deny having a condition that he associated with mental deficiency. He preferred to believe that his peculiar behavior and memory loss were symptoms of an emotional or psychological disorder. Some physicians hearing of his problem were inclined to agree with him, a complicity based on the difficulty in distinguishing some types of seizures from psychiatric phenomena.

Carl's denial that he had epilepsy is a common response, but there is no way to anticipate how any individual will react to the diagnosis of epilepsy. Marianne, a 25-year-old medical technician with transient episodes of numbness on one side of her body, was relieved to discover that her problem was an unusual type of seizure disorder called focal sensory seizures. She had feared that the peculiar sensations were evidence of a mental illness; and, unlike the businessman, Marianne found the prospect of "going crazy" much more terrifying than having seizures.

Although seizure disorders come in many different types, some features occur with striking frequency, and some attacks appear remarkably similar in many different people. Recurring features in different individuals form the basis for classifying seizure types (Table 2). Classification is useful because it provides a basis for choosing effective therapies. Some types of seizures, such as generalized absence seizures of childhood (also called petit mal or generalized nonconvulsive), are remarkably consistent from person to person. This makes them relatively easy to identify and simplifies the choice of

TABLE 2
Types of Seizures

Generalized	Partial
Convulsive	Simple
Nonconvulsive	Complex

treatment. Other seizure types are quite variable from individual to individual, although the seizure experienced by any one person is likely to have similar features each time it recurs. Complex partial seizures occur at any age, are extremely diverse in character, and consequently may be very difficult to identify in their least common forms. Deciding what specific form of seizures a person has may not be at all simple, but making an accurate diagnosis is worth the effort because the diagnosis in large part dictates the therapy, determines the outlook, and provides insight into the problems likely to be faced by the affected person and his family.

Provocative Stimuli and Seizure Thresholds

Epilepsy by definition involves recurrent seizures or at least the risk of recurrent seizures. A person who has had only one seizure does not necessarily have epilepsy. An isolated seizure may be nothing more than a one-time response to a head injury, nervous system infection, or chemical imbalance (such as low blood sugar, low levels of calcium or magnesium, or drug overdose). After recovering from these conditions, the person may be at no greater risk of seizures than people in the general population. Even a person who has had two or more seizures that were provoked by a stimulus likely to produce seizures in anyone, such as a high-voltage electric shock, does not have epilepsy. Women with complicated pregnancies that result in high blood pressure and kidney disturbances may

have seizures—a condition called toxemia of pregnancy or eclampsia—but these women would not be described as having epilepsy. They might have seizures each time they develop eclampsia, and they might develop eclampsia each time they get pregnant, but the seizures are attributable to a temporary condition, and after it ends their risk of seizures falls back to normal. Therefore they do not have epilepsy.

But what is a “normal” risk of seizures? Any person, regardless of how normal his nervous system is, can be stressed sufficiently to evoke a seizure. Severe sleep deprivation, electrical shocks, dehydration, head trauma, sunstroke, alcohol abuse, and other physical stresses can all provoke seizures in people whose brains are perfectly ordinary. How resistant we are to seizures under conditions that are known to provoke them is variable from individual to individual, but we all have a point beyond which our nervous systems cannot maintain organized activity. That is the point at which a seizure occurs.

The person with epilepsy is at risk for recurrent seizures *without* these predictably provocative stimuli. That the seizure disorder is completely controlled with medication does not change the fact that the person has epilepsy. If stopping the medication may reasonably be expected to place the person at risk of recurrent seizures, that person has epilepsy.

Epilepsy itself is not hereditary, but some nervous system disorders that cause epilepsy are inherited. In a given family, one member may have only a single seizure, and after that, if she takes medication, she may remain seizure-free for the rest of her life. We would still diagnose her as having epilepsy if we know that another member of her family has seizures. She is at higher-than-normal risk because of her personal and family history.

Sometimes a person with a family history of epilepsy will have only one seizure and then remain seizure-free for the rest of his life, even without medication. He is spared further attacks either because he is not as vulnerable to stimuli that

evoke seizures as are other people in his family (in which case the label “epilepsy” may not be appropriate for him) or because he is almost never exposed to the stimuli to which they are vulnerable.

What will trigger seizures in people with epilepsy is as variable as the form the seizures may assume. Starvation, dehydration, and exhaustion may be required to provoke attacks in one person, while a single night without much sleep may provoke seizures in another person with the same type of epilepsy. In most cases there is no obvious explanation for the difference. Even closely related people whose heredity makes them seizure-prone may require dramatically different conditions for seizures to occur. One child with generalized tonic-clonic seizures that develop only after several days of sleep deprivation may have a brother whose seizures occur whenever he sees flashing lights.

Sleeplessness, physical exhaustion, trauma, infection, and alcohol abuse are common precipitants of seizures in people whose epilepsy had been well-controlled previously. But the most common reason for recurrent seizures is failure to take one’s antiepileptic drugs as prescribed (Table 3). All of these provocative stimuli and situations must be avoided to minimize the risk of seizures. For most people this means developing daily routines that eliminate irregular hours and excessive burdens and that ensure that one does not skip medications. It is also important to pay extra attention to health issues and personal hygiene. Dental problems, foot infections, colds, and other common illnesses can rapidly escalate from minor annoyances to major health threats by evoking seizures.

In fact, in a person with epilepsy, an increase in seizures may be the first sign of another unrecognized health problem. For example, nighttime (nocturnal) seizures may be the first indication of a gum infection. Uncontrollable seizures that disappear when the patient is admitted to the hospital for closer observation may indicate well-concealed alcohol