There are many myths and misconceptions in the public mind that often have a negative impact on people with epilepsy as well as on their families and friends. The facts about epilepsy pose sufficient challenges without creating even more issues arising out of errors, speculation, and misstatements. In this chapter, I will try to correct some of those misunderstandings.

What follows is a quick historical overview of epilepsy, showing how the thinking about this condition has evolved over time. I will address some of the specific myths about epilepsy and provide the truth, which in many cases is much more comforting and reassuring. Finally, I will talk about the societal stigma that often accompanies epilepsy.

• • • Fast Fact • • •

About 60 million people around the world have epilepsy.

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A Brief History of Epilepsy

The Distant Past

Accounts of epilepsy date back thousands of years before the Common Era. Indeed, there exists a Babylonian tablet, dating from around 2000 BCE, that actually records various seizure types. At that time, however, epilepsy was understood only as a spiritual condition, which had to be dealt with through religion.

In 400 BCE, Hippocrates wrote the first book on the subject of epilepsy, *On the Sacred Disease*, in which he debunked the common belief that epilepsy was a form of supernatural condition. He explained that it was caused by naturally occurring disorders in the brain, not by curses or prophesies. Epilepsy was also mentioned in biblical times, and the Bible itself refers to the symptoms of epilepsy in the gospel of Mark.

In some early societies, people with epilepsy were considered to be under the influence of the changing phases of the moon. This led to the term *lunatic*, which in Latin means moonstruck, or crazy. It was common for people with epilepsy to be outcasts from society, and they were frequently punished. Even so,

Who Gets Epilepsy?

Among all people with epilepsy, the gender breakdown is 48 percent female and 52 percent male. There are two times in life when epilepsy is more likely to occur: during childhood and after the age of 55. In the United States, about 9 out of every 1,000 people are treated for epilepsy in any given year, and up to 5 percent of the world’s population may have one or more seizures at some time in their lives.
over time many people with epilepsy have risen to great heights despite their condition.

In colonial America, a person having a seizure was thought by some to have been overtaken by a demonic spirit. This superstition led to tragic events in Salem, Massachusetts, where, in the late 1600s, young girls would simulate seizures as part of their “proof” that certain women in the town were witches casting spells on children. And sadly, at that time and place any woman who happened to have seizures was branded as a handmaiden of the devil.

**Advances during the Last 200 Years**

The latter half of the 19th century saw great strides in the understanding of epilepsy, when English neurologists more clearly defined the medical basis of the condition and identified how seizures can alter consciousness and behavior. These breakthroughs were followed in 1904 by the coining of the term *epileptologist* (pronounced ep-ill-ep-TAHL-ah-jist) to describe a neurologist who specializes in this disease.

A milestone in the history of epilepsy was reached in 1929, when a German psychiatrist, Hans Berger, invented a method of recording the electrical activity in a person’s brain and printing it on a strip of paper. This technology, termed the *electroencephalogram (EEG)*, is still key to the diagnosis of epilepsy today.

Since 1940, many new drug discoveries have led to remarkable advances in the treatment of epilepsy. Of course, drug research continues to this day as scientists attempt to find new and better ways to help children and adults deal with the wide variety of epilepsies and seizure types.

In 1968, the Epilepsy Foundation of America was founded. Now called simply the Epilepsy Foundation, this group is dedicated to sharing information and promoting the health and well-being of people with epilepsy.
One of the most important technological advances in the last few decades has been the development of neuroimaging equipment, especially Magnetic Resonance Imaging (MRI). MRI can detect small brain lesions and other abnormalities, making possible the diagnosis of clearly specific epilepsies. This in turn opens the door for surgical intervention, when such an approach is appropriate.

A significant step forward was taken in 1990 when the Americans with Disabilities Act (ADA) was passed and signed into law. Before this law was enacted, some states had laws that did not allow people with epilepsy to marry or become parents. Shockingly, in some states it was possible to sterilize people with epilepsy without their consent! The ADA clearly prohibits discrimination on the basis of disability.
The Myths

Over the millennia, many myths about epilepsy and people who have epilepsy have arisen and, unfortunately, some myths persist. Perhaps one reason is that an epileptic seizure, particularly a grand mal seizure, with involuntary jerking movements of the whole body, can look pretty scary. And since the average person is rarely, if ever, exposed to such an event, misconceptions can easily grow among an uninformed public.

Here are some common myths and the very different realities.

The Myth: People with Epilepsy Are Crazy or Possessed

The reality: Epilepsy is a physical, functional problem that happens to occur in the brain. An epileptic seizure is an unprovoked and unpredictable interruption of a person’s daily life that can cause problems for the person experiencing it and those witnessing it. The fearful response to this physical disorder stems from the disorientation of witnesses who are unfamiliar with the sight of someone in the throes of a seizure.

Unlike the symptoms of most diseases, epileptic seizures imbue the patient with an otherworldly appearance, as if his body had been invaded by an unnatural force. Even though he’s unconscious during the seizure, he does not look like someone at peace. These factors feed the imaginations of witnesses and lead to highly erroneous conclusions.

The stigma of epilepsy endures today, even though we know much more about it and how to treat it than we did in decades and centuries past. As a result, few public figures such as actors, politicians, or other celebrities have stepped forward and admitted they have epilepsy. This is in notable contrast to the famous people with other diseases, such as AIDS and Parkinson’s, who
have been open about their conditions, and in some cases become spokespersons for their diseases.

We can only hope that this stigma will lessen over time as people learn more about epilepsy and its true nature. And on a personal note, I hope this book will make a contribution to that effort.

**The Myth: No Famous People Have Had Epilepsy**

**The reality:** Over the expanse of recorded history, there have been many people with epilepsy who have achieved great things in virtually all fields. A short list of these individuals includes:

- Socrates, Greek philosopher
- Alexander the Great, Greek general and statesman
- Julius Caesar, Roman statesman
- Napoleon, French emperor
- Lord Byron, English poet
- Fyodor Dostoyevsky, Russian novelist
- Vincent van Gogh, Dutch painter
- Alfred Nobel, Swedish munitions manufacturer, founder of the Nobel Prize
- Many, many more

One of the best known of all the world figures to have had epilepsy is Fyodor Dostoyevsky, the famous Russian writer. Unlike many others, Dostoyevsky never hid his epilepsy, and he used the condition as a theme in his novels. He gave several of his characters epilepsy, including Prince Myshkin, hero of *The Idiot.* Dostoyevsky described the effects of Myshkin’s seizures with penetrating accuracy.
The Myth: People with Epilepsy Aren’t as Smart as the Average Person

The reality: While the intelligence of the entire population of people with epilepsy is statistically slightly lower than the average, intelligence is a highly individual phenomenon. As noted earlier, there have been quite a few geniuses among people with epilepsy.

Epilepsy itself generally has little or no effect on a person’s ability to think, except during those brief moments when a seizure is taking place. Because epilepsy drugs act on the brain, physicians must be vigilant in ascertaining that drugs aren’t having a negative effect on learning, alertness, or functioning.

The Myth: People Who Have Seizures Can’t Handle High-Pressure, Highly Demanding Jobs

The reality: They often can . . . and they do.

Of course, there are some jobs that people with epilepsy should not pursue, such as a jet fighter pilot or a scuba diver. And some individuals are more affected by the stresses caused by certain jobs, such as the sleep deprivation faced by long-haul truckers, which can lower the threshold for seizures. But most professions can accommodate a person with epilepsy with little or no trouble.

There are countless people with epilepsy who work in the highest tiers of business, government, medicine, and virtually all walks of life. Because epilepsy is experienced so individually, each person must judge for herself the kinds of work she wants to do and is capable of doing.

The Myth: People with Epilepsy Appear Different—You Can Spot Such a Person on Sight

The reality: There is no physical manifestation of epilepsy outside the seizure itself. If other features are present, such as motor
or learning problems, they’re due to the underlying cause and not the epilepsy.

**The Myth: Epilepsy Is Often Accompanied by Other Physical Ailments, Handicaps, and Disabilities**

**The reality:** While epilepsy can occur along with other physical or mental problems, it often stands alone as the only significant medical issue a person has to confront. There is not necessarily an inevitable slide into other problems once epileptic seizures are diagnosed.

**The Myth: Epilepsy Is Contagious**

**The reality:** No, it isn’t. Enough said.

**The Myth: Epilepsy Can’t Be Caused by an Event that Happened a Long Time before the First Seizure Ever Occurred**

**The reality:** Actually, some epilepsies can develop slowly over time, in reaction to a trauma, illness, or some other occurrence much earlier in life.

**The Myth: It’s Possible to Predict Seizures If You Just Try Hard Enough**

**The reality:** Unfortunately, no, it isn’t. But research is active in this area, and we hope that someday it will be possible to help a patient know when a seizure is coming on.

In the meantime, some dogs are being trained to use their heightened senses to actually predict when a person’s seizure is about to occur. The dogs signal a warning by various means
that allows time for that person or others nearby to take precautions to ensure that no harm is done when the seizure arrives. Although this is a promising area of epilepsy prediction, there are no guarantees that any particular dog will be able to provide this service. So be very wary of claims made by dog trainers who may sell such a pooch under false pretenses.

**The Myth: Seizures Hurt**

**The reality:** Watching a friend or loved one experience a grand mal seizure is difficult, but remember that this person is unconscious and not in pain. After a seizure, a person may feel some discomfort resulting from muscle aches or stiffness, a bitten tongue, bruises from a fall, burns from contact with a stove or other heat source, or other scratches and scrapes. (See “Take Action: Responding to a Generalized Tonic-Clonic Seizure,” chapter 2.)

**The Myth: During a Seizure, a Person Is Likely to Swallow His Tongue**

**The reality:** It’s not possible. This misunderstanding can cause a serious problem if witnesses try to put something into an epileptic person’s mouth during a seizure in a misguided attempt to prevent that person from swallowing his tongue. Such an action can cause serious damage to teeth and gums, or it can cause breathing difficulties. In fact, you might even be bitten while contributing nothing to the person’s safety or well-being.

However, a person might sometimes bite his tongue or the inside of his cheeks during the seizure, causing soreness in those areas. These minor bite wounds heal quickly and aren’t a major concern beyond the discomfort they cause.
The Myth: Epilepsy Cannot Be Effectively Controlled

The reality: As seen in all the evidence presented in this book, there are many ways to treat, minimize, control, and even eliminate epilepsy when the conditions are right.

While there are some people whose epilepsy is so serious that the seizures just cannot be controlled, this group is becoming smaller as new treatments and medications are developed.

Also, the side effects from medications have become better appreciated, and we can use that knowledge to significantly improve the quality of life for most people with epilepsy.

What You Should Know

• Epilepsy is a physical, functional problem that happens to occur in the brain.

• Although epilepsy has been with us since antiquity, great strides in diagnosis and treatment have been made in the last 100 years.

• There are many ways to treat, minimize, control, and even eliminate epilepsy when the conditions are right.

• People with epilepsy may be smart, famous, and highly productive, just like anyone else.