Patient Care

At Cleveland Clinic, we believe the best medical care goes beyond the latest equipment and techniques. It also means compassion; we understand your concerns and are here to help. It means comprehensiveness, too. Because epilepsy affects so many aspects of the patient’s life — from the physical to the emotional to the social, and from the family to the workplace to the school — the Epilepsy Center’s comprehensive care approach addresses challenges across the board.

The Epilepsy Center brings together a coordinated, multidisciplinary team offering a broad range of skills and knowledge. As a result, patients benefit from a model of individualized care that integrates the expertise of our clinical staff and the capabilities of advanced technology. Beyond providing accurate diagnoses and effective treatments, we empower our patients to understand and manage their disease so they can enjoy fuller, more productive lives.

Cleveland Clinic Epilepsy Center Teams

Our teams include pediatric and adult neurologists/epileptologists, neurosurgeons, neuroradiologists, pharmacologists, physical, occupational and speech therapists, dietitians, neuropsychologists and psychiatrists, educational counselors and social workers, neuroscientists, biomedical engineers, nurses, and technologists. Here is how some of these professionals can help you:

NEUROLOGISTS/EPILEPTOLOGISTS

Epileptologists are neurologists whose specialized training in epilepsy gives them a deeper understanding of how the disease affects patients and helps them develop more effective treatment plans.
affects the central nervous system. Epileptologists at the Epilepsy Center:

• Use sophisticated technologies to help them accurately diagnose the type and cause of your own case of epilepsy.
• Medically treat your epilepsy, prescribing the most appropriate medication(s) for your condition.
• Make suggestions for treatment and symptom management.
• Answer all your questions and help with disability-related issues.
• Perform presurgical work-ups, using state-of-the-art technologies. If anticonvulsant medications have failed to control your epilepsy, or if they produce intolerable side effects, you may be a candidate for surgery. The determination involves a thorough medical history and physical examination, including brain-wave monitoring and other tests, to accurately localize the area of the brain where the seizures are originating. After identifying that specific source and assessing whether it can be safely removed without affecting important brain-controlled functions, the epileptologist (in consultation with a large group of epilepsy and epilepsy surgery specialists) makes the appropriate surgical recommendations.

NEUROSURGEONS
Our neurosurgeons and their surgical teams offer extensive experience, having successfully operated on thousands of patients of all ages with difficult-to-control epilepsies. The success of epilepsy surgery is measured in terms of its impact on seizure control and quality of life. Ten years after epilepsy surgery at Cleveland Clinic, 68 percent of patients who have undergone temporal lobe resection (removal of tissue) — the most common type of epilepsy operation — continue to be seizure free. In many other cases, seizure frequency is markedly reduced. Patients also report significant improvements in quality of life, including increased ability to perform daily activities and help you learn new, more satisfying approaches.

COGNITIVE AND BEHAVIORAL HEALTH SPECIALISTS
Epilepsy is frequently associated with depression, anxiety, memory lapses and other psychological/psychiatric disorders. For this reason, the Epilepsy Center has dedicated teams of adult and pediatric psychiatrists, social workers and neuropsychologists who diagnose these problems, treat them and provide support. Our teams offer:

• Diagnosis and treatment of epilepsy-related mental health disorders.
• Assessment of memory and cognitive functions and development of strategies to deal with neurocognitive disorders.
• Comprehensive pre- and postoperative diagnosis and treatment, should you become a candidate for surgery.
• Short-term counseling and referrals for ongoing assistance.
• Recommendations of community-based and national resources that provide epilepsy patients and their families with information and support.
• Long-term help to deal with the social and psychological implications of epilepsy and its treatment.

OCCUPATIONAL THERAPISTS
These specialists analyze how epilepsy affects the ways in which you perform your daily activities and help you learn new, more satisfying approaches.

Each year, our staff in Cleveland and in Weston, Florida, manages more than 6,200 adult and 2,300 pediatric patient visits.

THE DAY OF YOUR APPOINTMENT
When you come to the Epilepsy Center, please bring your appointment confirmation letter and test schedule with you. Your medical records are very helpful to us. Thus, it's important that you bring previous test results and studies that relate to your medical condition — such as from X-ray, angiography, MRI or CT procedures — and any related CDs or videos, including any video/EEG records. If you were hospitalized recently at a facility outside the Cleveland Clinic health system, please bring a copy of your hospital discharge summary sheet as well as other relevant hospital information. Your local physician can help you obtain these items.

Because management of your epilepsy is a shared responsibility of you and your doctors, we encourage you to take an active role by asking your own questions and raising any concerns you may have.

Since 2003, Cleveland Clinic has been a national leader in the use of fully integrated electronic medical records, which means that all your medical information and test results are securely saved and available electronically to everyone in our health system who is involved in your care. Thus, we ask you to fill out an online electronic questionnaire, which helps us to address the medical, psychological and social issues related to your condition and design the best diagnostic and treatment approaches for your personalized care. You may be able to access this questionnaire from home; please ask our receptionists, nurses or doctors about signing up for the MyChart option.

If tests are necessary at the Epilepsy Center, they will be scheduled, performed and analyzed as quickly as possible, but you should expect some waiting. You may want to bring reading material or toys for your children to help pass the time.

DIAGNOSIS
Because epilepsy manifests quite differently among patients, you will require individualized treatment. To evaluate your condition, members of the Epilepsy Center will take your medical history, perform a physical examination, and complete a series of neurological, neuroimaging and/or blood tests.

Medical History
Proper diagnosis and treatment rely heavily on the completeness and accuracy of your medical history. The physician needs detailed descriptions of your seizures as well as the sensations you may feel before and after these episodes. Others who have often seen you before, during and after seizures, such as family members and close friends, should be present to provide details, especially if your seizures involve loss of consciousness.

The physician may ask you the following questions, so it's best to consider them beforehand and be prepared.

clevelandclinic.org/epilepsycenter

Same day appointments available: 866.588.2264
Symptoms

• Do you experience a warning or aura before a seizure occurs?
• What is the first sign of the seizure?
• Do you lose consciousness?
• How long do your seizures last?
• How often do they occur?
• Which factors, if any, seem to trigger your seizures?
• At what age did your seizures begin?

History

• At what age did your seizures begin?
• What circumstances surrounded your first seizure?
• How have your seizures changed over time?

Prior Treatment(s)

• Which medication(s) have you taken?
• At what dosages?
• How effective were they?
• Did you experience any unacceptable side effects?
  If so, what were they?

Details of your past and present general health, as well as your family members’ overall health, will be needed. In addition, you will be asked about any alcohol or drug use. Significant events during the pregnancy, delivery and newborn periods may be explored.

Physical Examination

Your initial visit will include a general physical examination. By testing your muscle strength, reflexes, eyesight, hearing and ability to detect various sensations, for example, your doctors may develop a better understanding of the cause and nature of your seizures.

Tests

Your visit will also include a detailed neurological examination. The majority of these tests will be done on an outpatient basis. Procedures may include:

Electroencephalogram (EEG)  This recording of your brain waves is done by first attaching small disc electrodes to measured locations on your head. These electrodes are then connected to a recording device called an electroencephalograph. The EEG test, which typically takes about 90 minutes to obtain, is a digital recording of your brain waves that may provide critical information about the nature and location of any abnormalities.

Adults should sleep no longer than six hours the night before an EEG. This will help you or your child sleep during the EEG, which records brain waves during both wakefulness and sleep, and it will make the information we obtain as useful as possible. Toward that end, please do not eat or drink any caffeine-containing foods or beverages before the EEG. If natural sleep is not possible during the test, a mild sedative may be given. Because adults may be sleepy afterward, they should be accompanied by someone who can drive them home.

To ensure proper contact of the electrodes with the scalp, hair should be clean and free of any conditioners or styling products. Children as well as adults with developmental disabilities may show anxiety during placement of EEG electrodes, but our technicians are trained to handle such situations.

For patients with medication-resistant seizures, prolonged recordings in one of the two highly specialized Epilepsy Monitoring Units (EMUs) in Cleveland — one dedicated to adults and another located in our Children’s Hospital — may be needed. Our EMU in Weston, Florida, is dedicated to the evaluation of adult patients. These recordings may last several days and, thus, require hospitalization. Digital video recordings are done during these prolonged EEGs so that the data may be matched with symptoms and signs during a seizure. For more information regarding our Epilepsy Monitoring Units, visit clevelandclinic.org/epilepsyeducation.

Magnetic Resonance Imaging (MRI)  This advanced technique, which takes some 15 to 60 minutes to perform, uses magnetic and radio waves to generate a detailed view of the brain. Although an MRI carries none of the risks associated with X-rays, be sure to notify your physician if you are pregnant, have a pacemaker or other implanted metallic devices, or have had previous head surgery. Because movement may impair the quality of the images, children and anxious adult patients may require medication, by mouth or through a vein, to ensure that we obtain the best-quality MRI scans. Trained specialists perform the test and administer medications. Watch a video at clevelandclinic.org/epilepsyeducation to learn how to prepare for your MRI.

Blood Tests  These studies give our physicians a measure of the various compounds and cells normally present in your blood — a useful baseline for later comparisons. After you begin treatment with some anti-epileptic medications, you may need periodic blood studies to provide us with an understanding of how your body processes and reacts to these drugs. Cleveland Clinic’s diagnostic laboratories employ the most advanced techniques for prompt and accurate measurements.

Please take your seizure medications as usual. Do not delay taking them due to tests. Depending on your condition, epileptologists may recommend additional, more specialized tests or consultations with other clinicians such as a neuropsychologist, eye doctor or genetic expert. We will try to prearrange these consultations to better coordinate your care.
Treatment

The Epilepsy Center’s objectives are to control your seizures and restore your quality of life. In most cases, success is achieved through an accurate diagnosis and choice of the right type and dosage of anticonvulsant medication(s). In a few carefully evaluated and selected cases, epilepsy surgery may be recommended.

**DRUG THERAPY**

The most important advice to patients regarding drug therapy is to take your medications exactly as directed and to never suddenly change medications or stop taking them without consulting your physician. The type of anticonvulsant(s) you are given will depend on the type of epilepsy you have, and the dose prescribed will vary with age, weight, gender and other factors. As with any medication, you may experience side effects. Fortunately, most side effects, such as sleepiness or an unsteady walk, are mild and will soon pass. If serious side effects or other unexpected reactions occur, call your physician immediately.

It may take a few attempts before the best drug, combination of drugs or dosage is determined for you. During this adjustment period, frequent blood samples may be taken to monitor your blood-drug levels. Even after the optimal treatment is found, factors in your life may change, requiring later adjustments to further improve management of your seizures. Meanwhile, you should watch for side effects from these and other medications, including non-prescription products. For more detailed information regarding epilepsy medical treatment, visit the Epilepsy Center website.

Members of the Epilepsy Center teams regularly conduct research to evaluate the effectiveness of new treatments. If you do not respond to conventional drugs, you may wish to consider participating in a clinical trial of a new drug. Your physician and clinical trial coordinator would be glad to explain any particular study’s details to you, but your ultimate participation would be voluntary. For a listing of current clinical trials, visit clevelandclinic.org/neurotrials.

**SURGERY**

The majority of patients with epilepsy do not require surgery. But individuals whose seizures are unresponsive to drug therapy or who have intolerable side effects should be evaluated for possible surgical treatment.

To be considered for surgery, extensive neurological testing must show that the source of your seizures is in a well-localized area of the brain that can be surgically removed without causing damage to essential functions such as movement, sensation, vision, speech or memory. Seizure-free rates after surgery can range from 30 to 80 percent, depending on factors such as the patient’s age, general health and neurological specifics.

The principles of epilepsy surgery evaluation in infants, children, adolescents and adults are similar, for the most part. In children, however, age-related factors such as limited cooperation and maturing brain changes (which can complicate interpretation of EEGs and MRIs) pose additional challenges. On the other hand, pediatric patients are often best suited for epilepsy surgery, given that their still-developing brains can better adjust after tailored surgical removal of the epileptic region. Pediatric epilepsy surgery patients are offered comprehensive rehabilitation services at Cleveland Clinic Children’s Hospital for Rehabilitation.

To learn more about the Epilepsy Center’s special program in epilepsy surgery, please call for an appointment toll free at 866.588.2264 or visit our website at clevelandclinic.org/epilepsysurgery.

**Counseling**

Because your involvement in your own treatment is critical to its success, it is important to speak to a member of our epilepsy team about any problems or concerns you may have. For each patient seen by the team, control of seizures is only the first step in treating the whole person. Educational, social and psychological counseling are parts of the comprehensive treatment plan as well. If you or your child has a problem with school, work or daily activities, for example, specialists will be glad to help. They can guide your choices on medical issues such as long-term therapy and on nonmedical issues such as community services.

**EPILEPSY SUPPORT GROUPS**

Additional services offered by the Epilepsy Center include the Pediatric Epilepsy Support Group and the Adult Epilepsy Support Group, both of which address the needs of patients and of families caring for children who are afflicted with difficult-to-control epilepsy and its consequences. Members of the two groups include volunteer “ambassadors” and Epilepsy Center staff. The pediatric group conducts meetings for children who have undergone epilepsy surgery and hosts a biennial reunion where families come together to share experiences and receive valuable information from guest speakers, physicians, nurses and allied staff about life after surgery. For more information, visit clevelandclinic.org/epilepsysupport.

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The more you know about your diagnosis and treatment, the better care you can receive. Periodic follow-up exams with your doctor, physician assistant or advanced practice nurse are important, especially if your seizures prove difficult to control. During these visits, members of the Epilepsy Center team will evaluate how your medication is working and whether you are experiencing side effects.

Measuring the amount of seizure medication in your blood could be an essential part of a follow-up visit (if you are failing certain anti-epileptic medications). This test is usually completed once or twice a year but may be performed more or less often, if indicated. EEGs and neuropsychological and neuroimaging studies (such as MRI scans) may be an occasional part of your future course of treatment.

Controlling your epilepsy entails a long-term commitment by you and your caregivers. Periodic follow-up exams with your doctor, physician assistant or advanced practice nurse are important, especially if your seizures prove difficult to control. During these visits, members of the Epilepsy Center team will evaluate how your medication is working and whether you are experiencing side effects.

Educating yourself about your disease is an important part of the Epilepsy Center team's job. Our specialists also work with the public and with other physicians and healthcare professionals to promote a better general understanding of epilepsy and to share advances in treatment.

Follow-Up Visits

As part of these outreach efforts, members of the Epilepsy Center make frequent presentations to civic and corporate groups in order to help these organizations’ constituents better understand the causes and management of epilepsy. The Epilepsy Center works closely with the Epilepsy Association of Northeast Ohio (epilepsyinfo.org), the Epilepsy Foundation of America (epilepsyfoundation.org) and the Epilepsy Foundation of Florida (epilepsyfla.org).

To view and download more epilepsy-related information, visit clevelandclinic.org/epilepsyeducation.

Research

Members of the Epilepsy Center staff are actively involved in basic science, translational and clinical research projects intended to improve our understanding of epilepsy’s mechanisms, develop new treatment options and deliver better care to our patients.

Some of our patients may be presented with the opportunity to participate in epilepsy research through clinical trials of new drug therapies. If you choose to take part in a clinical trial, you can receive such therapies before they are available to the general public. To view a listing of the most up-to-date epilepsy clinical trials and enrollment information, visit clevelandclinic.org/neurotrials.

Other General Recommendations

The medical options now available for controlling seizures enable most patients with epilepsy to lead full, active and productive lives. Still, situations exist in which you have a responsibility to recognize and accept certain limitations.

Driving

Epilepsy-related driving laws differ among states and may change from year to year, but the basic intent is universal: If you have an active seizure problem, you should not drive, as the occurrence of a seizure could interfere with your control of the vehicle. Typically, it is your responsibility to tell your state Bureau of Motor Vehicles of any condition, such as epilepsy, that may affect your driving ability. Some states allow temporary licenses if your seizures have been under control for a period of time. Longer-term licenses are available in most states once you have had no seizures for three months to two years, depending on the particular state’s regulations. To view the requirements in your state, visit epilepsyfoundation.org/living/wellness/transportation/drivinglaws.cfm.

Working

Though employers sometimes worry about how workers with epilepsy will perform on the job, there is little need for concern if your seizures are well under control. If you have active seizures, however, you should avoid working in high places or operating potentially dangerous machinery, as the occurrence of a seizure may lead to injuries.

Many states assume liability for accidents that occur at work as a result of known illnesses such as epilepsy, in order to encourage the employment of people with these conditions. The associated funds, called second-injury funds, protect companies from liability for related medical costs. Rules covering eligibility for and use of these funds and workers’ compensation vary among states. People with epilepsy are also protected at the federal level by the Americans with Disabilities Act; visit eeoc.gov/facts/epilepsy.html.

Leisure and Sports

Because it is important for people with epilepsy to be physically active, participation in sports and other leisure-time pursuits is encouraged, though you should keep in mind the potential consequences of having a seizure while doing so. When swimming, for example, you should always have another person nearby who knows of your seizure risk and is trained in lifesaving techniques. Similarly, it is important to evaluate the risks before engaging in activities that involve water, heights or exposure to flickering lights.

Dental Work

Approximately 20 percent of patients using the anticonvulsant drug phenytoin (Dilantin®) have swelling of the gums. If you take...
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One year after temporal lobe resection, 80 percent of Cleveland Clinic patients continue to be seizure free; at the 10-year mark, 68 percent continue to be seizure free.

this drug, be sure to tell your dentist, and visit him/her regularly. Though most patients either have no swelling or control it through good dental/gum hygiene, it is sometimes severe enough to require gum surgery.

PREGNANCY

Please talk with your doctor before considering a pregnancy because women with epilepsy, particularly those taking anticonvulsant drugs, have a slightly higher risk of giving birth to children with birth defects. This risk may be reduced through folic acid supplements, pre-pregnancy evaluation of anticonvulsant medications and a customized plan for monitoring throughout the pregnancy. You should not stop or reduce your anticonvulsant drugs on your own before or during pregnancy; the risk to you and your baby from seizures may be greater than the risk of birth defects related to your medication. In any case, frequent physician visits, along with tests of blood anticonvulsant levels throughout your pregnancy, are important.

A well-planned and monitored pregnancy results in an excellent outcome for most women with epilepsy.

Making an Appointment

We encourage you to regularly see your neurologist at Cleveland Clinic Epilepsy Center and/or your local doctor. Often, the two will work together in caring for you. To schedule an appointment with your specialist at the Epilepsy Center in Cleveland, please call 216.229.5758 or toll free, 866.588.2264. For our Weston, Florida, location, call 954.659.5671. A letter confirming your appointment and listing your test schedule will be mailed to you. For more information, visit our website at clevelandclinic.org/epilepsy.

Special Assistance for Out-of-State Patients

Cleveland Clinic’s Global Patient Services has a Medical Concierge program that provides complimentary services to patients who travel from outside Ohio and Florida. For more information, call 800.223.2273, ext. 55580, visit clevelandclinic.org/concierge or email medicalconcierge@ccf.org.

Ronald McDonald House in Cleveland

Ronald McDonald House offers accommodations at a nominal charge to families of pediatric patients. Located across the street from Cleveland Clinic’s main campus, it provides a warm, homelike setting for families during their child’s stay at Children’s Hospital or during lengthy outpatient treatment. Families staying at Ronald McDonald House work together to make meals and handle basic housekeeping chores. Reservations are available on a first-come, first-served basis for overnight or longer stays. Call 216.229.5758.

eCleveland Clinic MyChart: Your Personal Health Connection

Epilepsy Center patients have the opportunity to enroll in MyChart, a secure online tool that connects you to personalized health information from the privacy of your home any time, day or night. All you need are Internet access and an email account.

As a MyChart user, you can:
• Answer the pre-visit health questionnaire.
• Review past appointments.
• Manage your prescription renewals.
• Manage appointment requests and cancellations.
• View your health summary, current list of medications and test results.
• Receive important health reminders.

If you experience an urgent health-related problem, do not attempt to use MyChart to communicate with your Cleveland Clinic healthcare team. Please call 911 or your physician’s office immediately.

Epilepsy Services at Cleveland Clinic Florida

Cleveland Clinic Florida’s epilepsy program is offered at the Weston campus, located just south of Fort Lauderdale. This program provides adult patients with the opportunity for comprehensive evaluation and diagnosis with state-of-the-art, all-digital EEG equipment.

EEG testing can be performed on an outpatient basis to detect disturbances in brain wave activity that may be causing seizures, after which a treatment plan is designed. In addition, Cleveland Clinic Florida offers inpatient video EEG monitoring to evaluate patients with difficult-to-control seizures who may be candidates for epilepsy surgery. Inpatient monitoring is used to find the location where seizures originate. When indicated, surgery may be performed by one of our epilepsy neurosurgeons in Cleveland or Weston.

Cleveland Clinic Florida also provides higher-resolution MRI using special protocols for epilepsy. This diagnostic tool may detect lesions in the brain that cause seizures. PET scanning, a noninvasive metabolic imaging technique, may be helpful for patients with partial seizures.

Among its epilepsy resources, Cleveland Clinic Florida maintains a self-contained, four-bed adult Epilepsy Monitoring Unit, with two additional mobile units, where diagnostic testing is conducted and patients can be monitored 24 hours a day, seven days a week. The unit is staffed by physicians, technologists and nurses specially trained in diagnosing and treating epilepsy patients.

To schedule an appointment with a Cleveland Clinic Florida epileptologist for testing and diagnosis, please call 954.659.5671.

For more information about our capabilities, visit clevelandclinic.org/FloridaEpilepsy.
Epilepsy Patient
Anne Crawford: A Full Life Free of Seizures

As a child, Anne Crawford could sense “that funny feeling” approaching: “I would wake up in the morning and know that some time that day, something was going to happen.”

The “funny feeling” was an aura warning of the “something”: an epileptic seizure. Well into adulthood, epilepsy stalked Anne, though she guarded her secret from all but her closest friends. “It was easier to not tell the truth,” she recalls. “Don’t let anybody close enough; it’s best they not know. That was my rule.”

After years of failed medications and uncontrolled epilepsy, marked by as many as 15 seizures a day, deliverance arrived. Anne met with Imad Najm, MD, Director of Cleveland Clinic Epilepsy Center, who told her that she might be a candidate for brain surgery: “It was the happiest day of my life when I got the call and heard, ‘You have been accepted as a candidate for brain surgery ... Dr. Bingaman will see you next week.’”

On October 14, 1999, William Bingaman, MD, removed the section of the left temporal lobe where Anne’s seizures originated. Every year since, she and her husband, Scott, have celebrated that special day.

“Our wedding anniversary is secondary,” she says. “We believe it was October 14 that changed our life for the future.”

Indeed. After repeated warnings against pregnancy during the years she was on medication, Anne gave birth to a son in April 2004. “I can’t describe what it’s like when you’ve spent your life planning on not having children — and, all of a sudden, you get this gift,” she says. “Scotty was a gift, which I would never have received if the surgery had failed. We call him our miracle baby.”

The family welcomed a second miracle with the March 2009 arrival of daughter Kara.

Today, Anne Crawford is a busy wife and mother with a private legal practice. One final fact makes all the rest possible: “I’ve been seizure free since October 14, 1999.”