



Clinical Practice Guidelines

Epilepsy

Program Update: 01/31/2015

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**Accordant Clinical Practice Guidelines:
Epilepsy**

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CONCISE REVIEW CLINICAL PRACTICE GUIDELINES: EPILEPSY

INTRODUCTION

The AccordantCare™ program works with health plans to assess, monitor, and support those with certain complex, chronic conditions. The focus of the program is to improve health outcomes and prevent or limit disease-related complications. AccordantCare offers unique services at no additional charge to the patients, putting them in a strong position to adhere to their treatment plan.

There are several ways AccordantCare augments physicians' efforts. Through regular telephone contact, AccordantCare nurses:

- Keep patients informed about the disease process
- Coach patients in self-motivation and self-care skills
- Encourage patients to alert their physician when new symptoms arise
- Direct patients to resources that help pay for medication, transportation, home modifications, etc.
- Ensure preventive and screening measures are accomplished
- Provide emotional support to patients and caregivers
- Screen for depression
- Find local support groups

We invite physicians to make use of the services offered by AccordantCare and to suggest ways we can further patients' treatment goals. To offer feedback, get more information, ask questions or voice concerns, call toll-free 1-800-948-2497 to speak with a program representative from 8 a.m. to 9 p.m., Monday through Thursday, and from 8 a.m. to 5 p.m. on Friday, Eastern Time. Messages left after hours will be returned the next business day.

Intent of Guidelines

The purpose of this Clinical Practice Guideline is to describe current patterns of practice where there is no fully established national guideline for diagnosis and management. It is not meant to dictate care of patients. Decisions about care are made by the physician and the patient based on the individual needs of that patient.

A patient's healthcare plan may or may not pay for the all medicines, tests, equipment, or services mentioned in this document. Benefits should be checked with the individual's healthcare plan to assure payment.

DISEASE OVERVIEW

Definition of Epilepsy

A 2013 ILAE (International League Against Epilepsy) task force proposed a "practical or clinical" definition of epilepsy. In this definition, epilepsy is a disease of the brain with any of the following conditions:

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- at least two unprovoked seizures occurring more than 24 hours apart;
- one unprovoked seizure and a probability of further seizures similar to the general recurrence risk after two unprovoked seizures (risk of about 75% or more);
- at least two seizures in a setting of reflex epilepsy (i.e., provoked by immediate transient stimuli, such as flashing lights).

Epilepsy is considered to be no longer present for individuals who had an age-dependent epilepsy syndrome but who are now past the applicable age, or for those who have remained seizure-free for at least 10 years off anti-seizure medicines, provided that there are no known risk factors associated with a high probability (>75%) of future seizures.¹

A seizure is a clinical symptom—such as a convulsion, loss of consciousness, strange sensations (e.g., peculiar smell, tingling), or a staring spell—caused by a disruption of the normal electrical system of the brain.² The ILAE defines an epileptic seizure as a “transient occurrence of signs and/or symptoms due to abnormal excessive or synchronous neuronal activity in the brain.”³

Because epilepsy is usually defined as a condition of recurrent (more than one) unprovoked seizures, a single seizure is not epilepsy. However, a single seizure in the presence of a brain disorder known to be associated with recurrent seizures, such as a brain tumor, epileptic genetic syndrome, or stroke, may be diagnosed and treated as epilepsy.⁴

Seizures that are provoked by specific causes, such as alcohol withdrawal, drug abuse, diabetes, a low serum sodium, or any other transient condition—even if they are recurrent—are not considered to be epilepsy. Similarly, seizures associated with high fever in children (febrile seizures) or seizures due to preeclampsia are not considered to be epilepsy.

In addition to epileptic seizures, which are caused by paroxysmal electrical discharges, patients may have other behaviors that look like seizures, but are not. These may be called nonepileptic seizures, pseudoseizures, psychogenic seizures, or nonepileptic events. These “seizures” have nothing at all to do with epilepsy, but may be mistaken for epileptic seizures. They are usually psychiatric in nature. The behavioral symptoms of nonepileptic seizures can be very similar to those triggered by epileptic seizures.

Prevalence of Epilepsy

One in ten individuals in United States will have a seizure during his or her lifetime.² About 2.3 million people in the United States have epilepsy,² with a reported prevalence of 1.1% to 2.2%.⁵ Doctors diagnose about 200,000 new cases of epilepsy each year.²

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Over half (57%) of the people presenting with a first seizure are under age 25, and 71% of these are 15 years old or younger.⁵ The lifetime risk of developing unprovoked epilepsy by the age of 80 ranges from 1.4% to 3.3%.⁶

However, the incidence of epilepsy is changing as our population ages. The onset of epilepsy is more common in the elderly than in any other age group, and more than 6% of all nursing home residents are being treated for seizures or epilepsy.⁷

Sudden Unexpected Death in Epilepsy (SUDEP)

People with severe epilepsy can die unexpectedly without a clear cause. It is usually unobserved when the person is asleep and alone.⁸ Based on current knowledge, the most effective means of preventing SUDEP is to:

- reduce the frequency of seizures (especially the generalized tonic-clonic type⁹) through optimized epilepsy care¹⁰;
- stay with the person until full consciousness is restored following a tonic-clonic seizure⁸
- maximize medication adherence^{8,10};
- avoid seizure triggers such as sleep deprivation and heavy alcohol use^{8,10};
- introduce treatment changes in a gradual manner and when switching, introduce the new drug before withdrawing the old⁸;
- consider benefits of intrusive monitoring, but weigh against the benefits of independent living⁸;
- avoid unnecessary polytherapy¹⁰; and
- consider epilepsy surgery in appropriate candidates in a timely fashion.¹⁰

Classification of Seizures & Epilepsy

The International League Against Epilepsy views its classification system of seizures and epilepsy syndromes as a dynamic, “continuing work in progress.”¹¹ In 2010, in an effort to forge concepts and terminology that reflect current advances in our understanding and knowledge of epilepsy, the ILAE formally abandoned its 2006 classification structure and proposed new classifications and terminology.^{11,12}

The 2010 revised classification system is still being evaluated. Problems still exist with the revised terminology, and change is occurring slowly. The 2010 ILAE revised classification system entails little or no change in what healthcare providers do in daily practice—that is, diagnose and treat individual patients. In fact, the implications of the 2010 ILAE changes for patient care are minimal.¹¹

Epileptic seizures can be classified into two broad groups based on where in the brain they begin. Generalized seizures result from abnormal electrical activity on both sides of the brain.¹³ They are now thought of as originating at some point within and rapidly engaging bilaterally distributed networks.¹¹ These seizures may result in loss of consciousness, falls, or massive spasms.²

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About 6 of every 10 people with epilepsy experience focal (also called partial) seizures, which begin on one side of the brain.¹³ Focal seizures are now thought of as originating within networks limited to one hemisphere.¹¹

About 12% to 30% of the adults who are newly diagnosed with epilepsy present with status epilepticus.¹⁴ The most commonly accepted definition considers any seizure (or seizures) that lasts 30 minutes or longer to be status epilepticus.^{14,15} This seizure duration is being challenged as being too long, however, and now any seizure that lasts longer than five minutes should be treated as an emergency to prevent status epilepticus.¹³

DIAGNOSIS OF DISEASE

Clinical History & Examination

The first steps in evaluating an individual with possible epilepsy is to determine if the person has actually experienced an epileptic seizure, and if so what type(s), and is it the first seizure?^{5,6} It must be confirmed that the patient has not experienced some other episode such as fainting, breath-holding (in children), low blood sugar, a transient ischemic attack, or a nonepileptic seizure. A diagnosis of epilepsy requires that the person has experienced recurrent epileptic seizures, that is, at least two unprovoked seizures that occur at different times. However, a single seizure with a neurological diagnosis associated with seizures, such as stroke or brain tumor, may be diagnosed and treated as epilepsy.⁴

The patient should be asked about a family history of seizures, birth complications, recent medications, injuries to the head, drug or alcohol use, symptoms of cancer, fever-related convulsions, etc.⁵

A physical exam should be performed to look for signs of disorders associated with epilepsy including signs of

- head trauma;
- ear or sinus infections (can spread to the brain);
- congenital abnormalities;
- neurologic abnormalities;
- cancer; and
- drug or alcohol abuse.

Patients require a complete neurologic examination, emphasizing finding signs of brain disease.¹⁶ Among other things, a neurologic exam assesses the patient's¹⁷

- motor and sensory skills;
- the functioning of the cranial nerves;
- hearing and speech;
- coordination and balance; and

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- changes in mood and behavior.

Signs and Symptoms

The signs and symptoms of the main types of seizures are:

Seizure type	Signs and Symptoms
Focal onset (partial)	
Simple focal	<ul style="list-style-type: none"> • seizure may begin with motor, sensory, autonomic, or psychic signs and symptoms, depending on the location of the electrical discharge • consciousness is not impaired¹⁸
Complex focal	<ul style="list-style-type: none"> • seizure may begin with no warning or with motor, sensory, autonomic, or psychic signs or symptoms • consciousness is impaired • automatisms (e.g., lip smacking, patting, bicycling movement of legs) • seizure is often followed by a period of confusion¹⁸
Secondarily generalized focal (tonic-clonic, or grand mal)	<ul style="list-style-type: none"> • may begin with motor, sensory, autonomic, or psychic signs or symptoms • consciousness is lost • stiffening (tonic) and jerking (clonic) of muscles • rhythmic (clonic) jerks subside slowly • patient is comatose after seizure and recovers slowly • tongue biting and/or incontinence may occur¹⁸
Generalized onset	
Absence (petit mal)	<ul style="list-style-type: none"> • seizure begins rapidly with a brief period of unresponsiveness (average, 10 seconds) and rapid recovery • there may be increased or decreased muscle tone, automatisms, or mild clonic movements • seizure can be preceded by hyperventilation • age at first seizure, 3 years to 20 years¹⁸ • characteristic EEG findings
Primarily generalized tonic-clonic (grand mal)	<ul style="list-style-type: none"> • loss of consciousness occurs without warning or is preceded by myoclonic jerks • clinical features are similar to those of a secondarily generalized focal seizure¹⁸

Tests for Epilepsy

(EEG) Electroencephalograph

After the patient history and neurologic exam, the EEG is the most influential tool in the diagnostic process.¹⁹ An American Academy of Neurology (AAN)

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evidence-based review recommends considering an EEG as part of the evaluation of an adult with an apparent unprovoked seizure because the test has a substantial yield in predicting seizure recurrence.⁶

EEG Video Monitoring

EEG video monitoring allows for the simultaneous tracking of both the clinical and electroencephalographic signs and symptoms of seizures. EEG video monitoring is used to make the diagnosis of epilepsy in difficult cases as well as in the evaluation of patients for possible epilepsy surgery. It may also be used to monitor patients in status epilepticus or used to detect occult seizures in patients with altered mental status, such as in comatose patients in the intensive care unit.

Other Laboratory Tests

Blood samples to screen for metabolic disorders that may be associated with seizures¹³ such as glucose abnormalities and low blood sodium.⁵

If substance abuse is suspected, blood and urine tests for toxins.^{5,16}

SCN1A testing should be considered in people with possible Dravet syndrome²⁰

A serum prolactin test may be useful in older children and adults to differentiate a generalized tonic-clonic seizure or complex focal seizure from a nonepileptic seizure.^{5,21}

A lumbar puncture may be indicated for people with a history or signs and symptoms of a central nervous system infection (such as meningitis or encephalitis).^{5,16} A lumbar puncture is also indicated for patients with a compromised immune system,⁵ and it's mandatory for all those infected with HIV (human immunodeficiency virus).¹⁶

Pregnancy testing should be performed for premenopausal women.⁵

Imaging Studies

Various brain imaging procedures are important tools that assist in the diagnosis of epilepsy, including¹³

- MRI (magnetic resonance imaging)—the preferred imaging method in nonemergency situations,⁶ with greater sensitivity than CT⁵;
- CT (computed tomography)—the preferred imaging method in emergency situations, more accurately detects acute bleeding⁵;
- PET (positron emission tomography) and fMRI (functional MRI)—used to monitor the brain's activity and detect functional abnormalities¹³;
- SPECT (single photon emission computed tomography)—used to detect seizure foci¹³; and

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- MEG (magnetoencephalogram)—can detect signals from deeper in the brain, MEG measures magnetic signals to monitor brain activity.¹³

Established Diagnostic and/or Assessment Criteria

The Quality of Life in Epilepsy Inventory has 89 questions that assess the effects of epilepsy, including the patient's mental and emotional health and role limitations.²² A shorter version (Short Form-36) is more general, more convenient, and used more frequently.²²

APPROACH TO MANAGEMENT OF PRIMARY CONDITION

Goals of Treatment

It's important to begin treatment as soon as possible because some research indicates that treatment may be less successful once seizures become established.¹³ The goals of therapy for adults and children with epilepsy are to

- completely prevent seizures^{16,23};
- avoid or minimize adverse side effects of AEDs^{16,23};
- maintain the best quality of life²³; and
- if possible, find a single medicine with an easy-to-follow dosing schedule.¹⁶

Summary of General Management

Antiepileptic drugs (AEDs) are the first treatment choice for the vast majority of patients with epilepsy. Now more than two dozen different AEDs are available and FDA approved. Other treatment options, usually tried only if AEDs fail to control epilepsy, include:

- surgery;
- diet;
- implanting a device to stimulate the vagus nerve¹³; and
- the NeuroPace RNS[®] System, a device approved by the FDA in 2013 that is implanted in the brain and combines a seizure sensor and stimulation.²⁴

When clinical and serological clues suggest an autoimmune basis for medically intractable epilepsy, the early use of immunotherapy may improve seizure outcome.²⁵

Referral to Specialized Epilepsy Centers

Patients who have refractory epilepsy or persistent side effects should be referred to a third or fourth level specialty epilepsy center. The National Association of Epilepsy Centers (NAEC) guidelines recommend referral to a specialized epilepsy center when:

- the diagnosis of epilepsy is in question or if psychogenic nonepileptic events are suspected—should be referred as appropriate early in the evaluation process for diagnostic purposes;

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- a patient's seizures have not been brought under control after three months of care by a primary care provider—should be referred to a neurologist or to an epilepsy center if locally available;
- a patient's seizures have not been brought under control after 12 months of care by a general neurologist—should be referred to a specialized epilepsy center with an epileptologist.²⁶

Transition of Care

The transition of adolescents with epilepsy from pediatric care to adult care, especially for those with cognitive impairment, is complex and can be filled with turmoil for both patients and their advocate parents. It is important to develop an individualized transition program for these patients in advance.²⁷ It seems reasonable to develop in advance a transition of care program for all adolescents with epilepsy. Some specialist in epilepsy care for both pediatric and adult patients, thus avoiding the trauma of transition.

Treating Epilepsy with AEDs

Selecting an AED

AEDs are selected primarily based on the type of seizure being treated and can be divided into broad-spectrum drugs (good efficacy in focal and generalized seizures) and narrow-spectrum drugs (preferentially effective in focal or generalized seizures).²⁸

In addition to the AED's efficacy, many doctors consider other variables when selecting the best medicine for a patient,²³ including

- the type of seizure and how frequently the seizures occur¹³;
- the individual's age, gender and lifestyle¹³;
- the patient's genetic background²³;
- the patient's comorbidities²³;
- the likelihood of pregnancy for a woman¹³;
- the comparative cost of the drug²³;
- the drug's ease of use;
- drug-drug interaction potential, especially in elderly patients²⁸;
- the drug's potential toxic reactions and side effects¹⁶; and
- the convenience of dosing.¹⁶

Therapy with AEDs

Therapy usually begins with an average dose of a first-line AED.¹⁸ If the average dose of a first-line drug controls the individual's seizures and doesn't cause untoward side effects, therapy continues as started.¹⁸ Frequently the dose must be adjusted because the seizures aren't controlled or the side effects are intolerable.¹⁸ It is important to treat the individual patient—whose needs may or may not fall within the established reference therapeutic range for an AED.

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For many people, seizures can be controlled with just one drug at the optimal dosage.¹³ However, when increasing dosage leads to intolerable side effects without achieving seizure control, another first-line or a second-line AED may be added.¹⁸

One approach is to choose two drugs with complementary mechanisms of action, for example, combining a sodium channel blocker like phenytoin with a GABA-ergic drug like valproate.¹⁸ In the past, the prevailing wisdom has been to try at least two different monotherapies before treating a patient with two AEDs at the same time.¹⁸ Recently combinations of an older, first-line drug and one of the newer AEDs seem to be safe and effective.¹⁸

Discontinuing Therapy with AEDs

About 70% of the children and 60% of the adults whose seizures are controlled by AEDs can gradually discontinue their drug therapy at some point.¹⁶ The decision to stop treatment is often more difficult than the decision to begin treatment.²⁹ The decision to discontinue must be individualized and should consider the probability of seizures recurring, the consequences of recurring seizures, and the advantages of discontinuing the medicines (e.g., avoiding their side effects and drug interactions, the cost of the AEDs, etc.).¹⁸ Many doctors believe it's better to continue AEDs as long as signs of seizure activity persist on an EEG.³⁰ Patients should be advised to never discontinue their seizure medication without their doctor's advice and supervision.¹³

Switching Between Brand-name and Generic AEDS

Prescribing generic medicines is an important tool in lowering costs and ensuring the effective use of healthcare resources.³¹ However, the decision to switch from a brand-name AED to a generic AED should be made by the doctor and patient together after considering the possible benefits and risks. Patients who switch from one AED to another—whether from a brand-name to a generic AED, from one generic AED to another generic, or from one brand-name AED to another brand-name—should be carefully monitored.

Treating Status Epilepticus with AEDs

Few randomized controlled trials of using AEDs to treat status epilepticus exist.¹⁴ However, a recent review of the existing randomized controlled trials concluded, even with limited data, that intravenous lorazepam (Ativan[®]) is the first-line drug of choice and should be favored over diazepam (Diastat[®]), fosphenytoin (Cerebyx[®]) or phenytoin (Dilantin[®], Phenytek[®]).¹⁴

The most common form of status epilepticus is tonic-clonic status epilepticus.¹⁸ If monotherapy doesn't control the seizures, they can usually be managed with a combination of intravenous diazepam or lorazepam plus intravenous fosphenytoin, the prodrug of phenytoin, which is safer.¹⁸ If seizures last more than 10 minutes after the first treatment, it's recommended to try repeated doses

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of the benzodiazepine.²⁹ If this fails, the patient should be intubated and admitted to an intensive care unit. The patient should be treated with midazolam, propofol, or barbiturates, and the EEG should be monitored.²⁹

Treating Refractory Epilepsy with AEDs

Advances in AED therapy have provided more options for treating epilepsy for which treatment appears to be inadequate—including combinations of drugs. Evidence indicates that trying one AED after another is more likely to be harmful than beneficial.³² Using two or more AEDs at the same time appears to involve a tradeoff: adding a drug can reduce seizures, but it can also cause more side effects.³²

However, many more patients with intractable epilepsy are likely to experience benefit than harm from polytherapy.³² These qualitative differences lead to the conclusion that polytherapy is preferable to sequential monotherapy for patients with treatment resistant epilepsy.³²

Refractory focal seizures: A recent systematic review and meta-analysis of data based on over 14,000 patients and 70 RCTs compared the new AEDs when used to treat refractory focal epilepsy. The most relevant findings of the study are:

- (1) Topiramate and probably levetiracetam are more efficacious in controlling seizure frequency (as measured by analysis of the responder rate), whereas gabapentin is less efficacious in comparison to all other new AEDs;
- (2) Tolerability (as measured by study withdrawals) was poorer with oxcarbazepine and topiramate, whereas gabapentin and levetiracetam are better tolerated; and
- (3) Globally, the frequency of the most common side effects is comparable between the new AEDs.

The differences found among AEDs were relatively small and could not lead to definitive conclusions about which new AEDs have superior effectiveness.³³

Refractory generalized seizures: Most patients with idiopathic (genetic) generalized epilepsy are easily controlled, and refractory cases are less common. On the other hand, refractory symptomatic generalized epilepsy (e.g., Lennox-Gastaut syndrome) is more devastating and is difficult to treat.

Recommended Nondrug Therapies for Epilepsy

In addition to AEDs, doctors have nondrug treatment options including surgery, vagus nerve stimulation, the NeuroPace RNS[®] System, and the ketogenic diet.

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Surgical Therapies

About 20% to 30% of patients with epilepsy are resistant to monotherapy or polytherapy with AEDs.¹⁶ Some epilepsy syndromes are known to be especially resistant to AED therapy.¹⁶ Surgery for these epilepsy patients is now widely accepted as an effective treatment option. Most complications after epilepsy surgery are minor or temporary and tend to resolve completely. Despite considerable evidence for its success and safety, surgery is an underused therapy for people with drug-resistant seizures.³⁴

An evaluation for surgery should be considered for patients with drug-resistant seizures if the seizures significantly interfere with their lives. It is not necessary that the patient have daily or even weekly seizures.³⁵ Every person being considered for epilepsy surgery must undergo a psychiatric evaluation.³⁶ A history of psychotic disorder is not a contraindication for epilepsy surgery provided the individual has appropriate psychiatric management and understands the risks, benefits, and limitations of surgery.³⁶ A candidate for surgery should have the operation as early as possible¹³ but only after a careful evaluation³⁷ at a comprehensive epilepsy center.^{30,37}

Surgical procedures for epilepsy include

- resections (e.g., anterior temporal lobectomy, focal neocortical resection, lesional resection, and hemispherectomy); and
- disconnection procedures (e.g., corpus callosotomy and multiple subpial transections).³⁸

Treating Refractory Epilepsy with VNS

When surgery is not an option, VNS (vagus nerve stimulation) is the AAN-recommended treatment. The FDA approved VNS in 1997 for “use as an adjunctive therapy” to reduce the frequency of seizures in adults and adolescents over 12 years of age with refractory focal onset seizures.

Pediatric patients less than 13 years of age with focal onset seizures and adult and pediatric patients with generalized seizures have also benefited significantly from VNS. VNS may be considered for treating Lennox-Gastaut syndrome.³⁹

Treating Refractory Seizure Disorder with the NeuroPace RNS System

In November 2013, the FDA approved the NeuroPace RNS[®] System for adults with intractable partial onset seizures. The device is implanted under the skull with one or two sensing and stimulating electrodes. These electrodes can detect abnormal electrical activity in the brain and deliver an electric shock to stop a seizure before it becomes clinically apparent.

Candidates for the NeuroPace RNS System will primarily be patients who would otherwise have surgery, but cannot due to more than one seizure focus or a seizure focus in a nonresectable area. The final results of the RNS System

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Pivotal trial—a prospective, randomized, double blind, sham trial of 191 patients with intractable focal epilepsy—confirmed that the median reduction in seizures in patients using the RNS System in the two years of postimplant follow-up was 44% at one year and 53% at two years. This represents a progressive and significant improvement with time.⁴⁰ The effectiveness of the NeuroPace RNS System has not been formally compared to the VNS.⁴¹

Treating Refractory Seizure Disorder with Diet

Guidelines for using diet as a treatment for epilepsy don't currently exist.²⁹ Two special diets, the ketogenic and the modified Atkins diet, improve seizure control in some patients.^{42,43} The modified Atkins diet was found to be effective and well tolerated in children with drug-refractory epilepsy.⁴⁴ A version of the ketogenic diet has been used successfully to treat some patients with intractable epilepsy since the 1920s.⁴²

Other Therapies for Epilepsy

Although one survey reports that about 40% of the people with epilepsy resort to complementary/alternative therapy (e.g., prayer, herbal remedies, acupuncture, yoga, meditation), there is little scientific evidence to support the effectiveness of these efforts.⁴⁵

PREVENTION AND MANAGEMENT OF COMPLICATIONS

Accordant helps patients prevent and manage complications by teaching early warning signs, encouraging adherence to treatment plans, offering supportive care, and recommending physician contact when needed. The goals and cooperative interventions below do not represent a comprehensive list of complications but reflects some of the more common clinical situations specific to epilepsy. General health topics (e.g., age-appropriate cancer screening) are beyond the scope of this document.

Goal: Promote Healthy Behavior

Cooperative interventions

- Provide educational resources that promote proper nutrition and exercise programs that help to prevent obesity and comorbid conditions such as heart attack/stroke.
- Encourage patients not to smoke and provide information and education on resources that help patients to stop smoking.
- Encourage flu vaccination/pneumococcal vaccination (polyvalent Pneumovax), unless contraindicated, to high-risk patients with epilepsy.
- Encourage parents of children with epilepsy to talk to their doctor about vaccinations.⁴⁶

Goal: Promote Self-Management of Condition

Cooperative interventions:

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- Inform patients that an Accordant nurse is available for incoming calls 24 hours a day.
- Provide information on national and community-based epilepsy foundations and resources.
- Provide an approved list of educational materials and Web sites during assessments and on an as-needed basis.
- Educate patients on their treatment options, benefits, risks, and side effects, to enhance adherence through informed decision making.
- Educate patients regarding the signs, symptoms, and prevention of seizure activity.
- Educate patients regarding the signs, symptoms, and prevention of common complications of epilepsy such as drug interactions, injury, and status epilepticus.
- Educate patients about the psychosocial complications of epilepsy including driving precautions.
- Counsel regarding activities that may lead to a seizure, i.e., sleep deprivation, substance abuse and AED nonadherence.
- Educate and support patient's family and/or caregiver.

Goal: Decrease/Prevent Recurring Seizures

Cooperative interventions:

- Explain to patients the importance of seizure control, not only to prevent seizures but also to avoid injuries, cognitive problems, and other issues.
- Monitor patients regularly and educate them about their physician's treatment plan to ensure their understanding.
- Educate patients regarding medications, correct dosages, indications, potential side effects and interactions.
- Monitor and enhance adherence with prescribed antiepileptic drugs (AEDs), including using a back-up plan for having medications on hand at all times.
- Advise patients not to switch AEDs without talking with their doctor, and monitor closely patients who do switch from one AED to another.
- Communicate to the physician a summary of reasons for patient nonadherence, if any.
- Communicate with physician when there has been a change in patients' clinical or functional status.
- Educate patients about potential seizure triggers and encourage the use of a seizure calendar to record the time, duration, after-effects, etc., of seizures.
- Work with patients to develop a seizure management plan that includes
 - keeping pertinent personal information current and handy;
 - having family members or friends who are willing to help;
 - keeping a seizure calendar and/or journal;
 - knowing what to do in a seizure emergency;
 - avoiding seizure triggers;
 - adhering to all medication schedules;

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- sharing information with healthcare professionals; and
- taking an active role in controlling their epilepsy.
- Monitor adherence to ketogenic or other seizure diet (such as the Atkins) where appropriate.

Goal: Prevent Seizure-related Injuries

Cooperative interventions:

- Provide a detailed home safety checklist designed for seizure patients.
- Provide an emergency checklist for the patient/caregiver, school nurse/teacher and employer on how to manage a seizure. Instruct on seizure first aid.
- Encourage patients to wear helmets if seizures are frequent and intractable.
- Advise the patient/caregiver on safety during each interaction.
- Advise patients to avoid certain activities (e.g., swimming alone, climbing) that might result in serious injury or death if a seizure were to occur during the activity.
- Encourage patients to be aware of driving rules and regulations for their state.

Goal: Address Women's Health Issues

Cooperative interventions:

- Educate the patient regarding potential medication interaction between AEDs and hormonal contraceptives; explain that certain AEDs may make hormonal contraception less reliable.
- Explain that AEDs may suppress sexuality.
- Inform patients that many women experience increased seizures that are related to their menstrual cycle.³⁷
- Educate women of childbearing potential that lamotrigine levels may decrease during pregnancy or when used with an estrogen-containing hormonal contraceptive.
- Educate women of childbearing potential regarding the risk of birth defects related to AEDs. Explain that while there is no firm ranking of the safety among AEDs during pregnancy, there is data to help guide physicians and patients as they make their choice.⁴⁷⁻⁴⁹ The best time to consider different AEDs at different doses is before pregnancy.⁴⁹
- Educate the patient regarding the need for family planning and genetic counseling.
- Recommend that family planning should include women of childbearing age taking at least 0.4 mg/day of folate.⁵⁰
- Educate patients regarding the special importance of medication adherence during pregnancy.
- Educate the patient regarding the special need for monitoring of AED drug levels during pregnancy, as levels may drop significantly, particularly with lamotrigine (Lamictal).

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- Educate the patient regarding the potential of seizure “triggers” during pregnancy.
- Educate the patient regarding the importance of vitamin K therapy during the third trimester of pregnancy if taking enzyme-inducing AEDs.⁵¹
- Educate the patient regarding breast-feeding and AEDs.
- Educate women taking AEDs about their increased risk for osteoporosis.

Goal: Promote Medication Safety Behavior

Cooperative interventions:

- Educate patients about their medication, its dosing, potential side effects and interactions.⁵²
- Advise patients not to accept generic substitutes for their AEDs without their doctor’s recommendation or approval.
- Monitor patients for drug-to-drug interactions and inform physician of any medication errors or unreported side effects.
- Counsel patients taking AEDs about their increased risk of suicidal thoughts and behavior.
- Monitor patients taking AEDs for any signs of suicidality and alert their doctor if any signs occur.
- Educate patients on the possibility of rash from newly added drugs; instruct patients to notify their physician of any history of rash and of any new rashes.
- Alert physician when the patient has a rash side effect.
- Encourage patients to carry all their prescription and over-the-counter medications when they visit their physician. This includes herbal medicines and other “natural” or alternative medicines.
- Monitor patient adherence with all appropriate laboratory evaluations.

Goal: Promote Coping with Condition

Cooperative interventions:

- Evaluate the adequacy of the patients’ support systems and work with physician, the patient, caregiver, family and health plan to correct any deficiencies.
- Educate the patient’s family about how to recognize a seizure emergency and how to make the proper response.
- Assist the physician in detecting the patient’s mood disturbances using a telephonic depression screening tool. Obtain the patient’s consent to notify and provide his/her physician with screening results. Facilitate a corrective plan as approved by the patient and physician.
- Enhance the patient’s access to support groups and encourage patient-physician communication.
- Monitor the patient for behavioral problems possibly associated with AEDs.
- Assess the patient’s quality and duration of sleep since sleep deprivation may increase seizures.

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Goal: Recognize Depression, Anxiety, and Suicidality and Provide Appropriate Treatment

Cooperative interventions:

- Educate patients to understand that the effective management of their epilepsy may include the early detection and management of any neuropsychiatric comorbidities (anxiety, depression, psychosis, cognitive dysfunction,) and on finding appropriate interventions for these conditions.
- Screen patients for depression and provide appropriate treatment and/or referrals.
- Educate patients, family and care givers about the signs and symptoms of depression and anxiety.
- Counsel patients, family and care givers that epilepsy may be associated with an increased risk of depression and suicidal thoughts or behavior.
- Warn patients taking AEDs about their increased risk of having suicidal thoughts or actions, some of which may be related to taking AEDs; advise them to talk to their physician or nurse as soon as possible if they experience suicidal thoughts or actions.
- If necessary, refer patients for psychiatric evaluation, but AED treatment should not be withheld, even in patients with positive suicidal risks.⁵³
- Monitor patients taking AEDs for any changes in behavior that might indicate suicidality.
- Counsel family and care givers to talk to the patient's physician or nurse as soon as possible if the patient experiences suicidal thoughts or actions.
- Counsel patients and family to consider cognitive behavioral therapy, if prescribed, as a treatment option for depression and anxiety.^{53,54}

PATIENT FOLLOW-UP

Ongoing follow-up with seizure patients to evaluate their status is essential. For example, follow-up with the patient may be helpful after home safety evaluations, physical therapy, or the acquisition of new durable medical equipment. Accordant can work with the patient to coordinate referrals, community resources, and government services. We also can collaborate with other healthcare professionals on behalf of the patient.

Please inform Accordant of any issues that require monitoring or follow-up with your patient so that we may effectively communicate the specifics of the physician treatment plan.

Examples of ways that physicians can facilitate Accordant follow-up include:

- Encourage patients to work with Accordant for education, information and self-care needs.

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- Inform Accordant of the patient's unique educational needs or barriers to care so that we can supplement your activities.
- Communicate to Accordant the physician-driven treatment plan or referral needs so that we can optimally support your activities.
 - Apprise Accordant of any issues that require monitoring or follow-up.
 - Communicate to Accordant any strategies to prevent injury or disease complications.
 - Work with Accordant to encourage and facilitate protective equipment as appropriate.
- Inform Accordant that a member is considering becoming pregnant or is pregnant.
- Communicate with Accordant throughout a member's pregnancy regarding the physician treatment plan, member adherence, and needed patient education.
- Inform Accordant of medications prescribed to the patient that require monitoring so that we can maximize patient adherence with the necessary testing.
- Communicate to Accordant any other activities that we can facilitate: for example, social worker evaluation, adult daycare services, transportation needs, assistance with obtaining drugs and supplies, etc.

PATIENT EDUCATION

List of approved websites

Epilepsy Foundation: <http://www.epilepsyfoundation.org>

International League Against Epilepsy: <http://www.ilae.org>

National Institute of Neurological Disorders and Stroke: <http://www.ninds.nih.gov>

American Academy of Neurology: <http://www.aan.com>

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