



EPILEPSY

MANAGING the DETAILS

COMPREHENSIVE EPILEPSY PROGRAM

UC DAVIS
HEALTH



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Introduction

UC Davis Health

As the region's only academic medical center, UC Davis Health System is charged with discovering and sharing knowledge and providing the highest quality of care to our community. Our depth of expertise and resources has enabled UC Davis to be one of U.S. News & World Report's "Best Hospitals" for over 15 years.

UC Davis Comprehensive Epilepsy Program

The UC Davis Health System is proud to be recognized as a "Level 4 Epilepsy Center" by the National Association of Epilepsy Centers. Level 4 Epilepsy Centers provide the most advanced level of care for individuals with epilepsy in the United States. Our program provides state of the art management for persons with epilepsy, including special needs patients, pregnant women, and the elderly. We maintain a four bed inpatient epilepsy monitoring unit and utilize sophisticated imaging equipment. Research facilities promote basic science research as well as clinical trials.

Our Epilepsy Team

Our highly experienced team includes neurologists, epileptologists, neurosurgeons, neuropsychologists, neuroradiologists, nurse practitioners, nurses, as well as clinical and basic science researchers who focus exclusively on epilepsy. Some specialize in treating adults, while others specialize in treating children.

Although epilepsy can affect daily life, most people with epilepsy lead normal lives. It is our aim to educate and support patients, families and medical professionals about managing epilepsy. Our goal is to assist individuals with epilepsy to live without seizures or side effects from medications, thereby improving their quality of life. We have tried to answer the questions most frequently asked by our patients. Keep this booklet to refer to when you have questions in the future.

UC Davis Neurosciences Clinic

We are open Monday through Friday (excluding holidays) from 8am to 5pm. If you need assistance, please call **800-770-9288**.

When calling our office, please have the following ready:

- * A current list of your medicines, including doses. Carry this list in your wallet at all times.
- * The name and telephone number of your pharmacy.
- * Your UC Medical Record Number and date of birth.
- * The dates and symptoms of your seizures.

Messages

UC Davis Health System is an academic or teaching university. Our providers are also involved in lecturing, training, research and caring for hospitalized patients. Hence, they are in clinic for a limited number of hours each week. If you have an urgent message, please call and speak with our triage nurse who will contact your physician with the details of your situation. It may take several days to receive a response from your doctor regarding non-urgent matters.

Federal confidentiality (HIPAA) guidelines restrict our staff from giving information to anyone other than patients. Therefore, it is best when the patient contacts us directly. However, this might not always be possible. If your family member or friend calls our office, they will need to provide identifying information in order for our staff to discuss matters pertaining to your care.

After Hours, Weekends, & Holidays

If you need to speak with a neurologist after hours, call the hospital operator at **916-734-2011**.

Emergencies

For life-threatening emergencies, call **9-1-1**.

Urgent Appointments

If you feel that you have an immediate need, please call our office and speak to one of our advice nurses. They can arrange for an urgent appointment if necessary, or direct you to other sources of medical assistance.

Medication Refills

Please contact your pharmacy when you need refills of your medication. If you have no refills left, ask your pharmacy to fax **916-734-7188** for additional refills. **Please allow 5-7 working days** as your chart may need to be reviewed before refills are approved.

Forms—DMV, School, Employment, FMLA and other forms

Please allow **several weeks** for forms to be completed. Forms will not be completed unless the release of information section is signed and dated by patient and witnessed if required. Your doctor may need you to schedule an appointment in order to complete some forms. You may fax forms to **916-734-7188**. Forms cannot be completed on the day of your clinic visit.

State disability forms are processed by the UCD Disability Coordinator, Medical Records Bldg 2nd floor, Monday to Friday, 8:00 am to 4:30 pm. Call **916-734-2293** to schedule an appointment. There is a \$10 fee.

Medical Records

University policy does not allow clinic staff or physicians to provide you with copies of your medical records. To obtain copies of your medical records, you need to contact the UCD Health Information Management Office at **916-734-5205**.

MyChart—access to your Electronic Medical Record

To obtain access to your electronic medical record, send an email to mychart.ucdavis.edu to request an **activation code**.

Obtaining Test Results

If your tests were done at UC Davis facility, please call our office to obtain test results.

If your tests were done at any other facility, please contact that facility to have them fax your results to us at **916-734-7188** as these results may or may not be sent directly to us.

If you had a MR scan done at a non-UC Davis facility, please obtain a CD disk with the images on it and bring it to your next UCD Neurology clinic visit.

Changes in medical insurance, PCP/Pediatrician, and/or contact information

Please contact us at once if you have a change in medical insurance, PCP/Pediatrician, and/or a change in your address or personal phone number as we may need to reschedule your diagnostic testing and/or clinic visits.

Radiology Films/X-Rays

To obtain copies of X-rays and scans (CT, MRI, PET, etc.) done at UC Davis, contact the UCD Department of Radiology Film Library at **916-703-2147**.

New Patient Appointments

If you have never seen a UC Davis Comprehensive Epilepsy Program physician, please have your primary care physician call **800-4 UCDAVIS** to make a referral for you to be seen.

Pediatric Appointments

For pediatric patient information, contact **800-770-9288** or the Physician Referral Center at **800-4 UCDAVIS**.

To Obtain a UC Davis Primary Care Provider

Call **1-800-2 UCDAVIS**.

Preparing For Your Clinic Appointments

- * *Bring your prescription bottles to all of your appointments - including vitamins, herbs and over-the-counter medications you take.*
- * *Keep notes about your seizures, medications and questions. Bring them to your visit. If you have difficulty communicating, bring a friend or relative with you.*
- * *We can best help you when you are honest about your condition and any problems you are having.*
- * *Be sure to attend your appointments. It may take several months to schedule another one if you miss your appointment.*
- * *Patients who arrive late can cause delays for those who arrive on time. If you arrive late for your appointment, you may be asked to reschedule.*



Understanding Epilepsy

What is Epilepsy?

Epilepsy is a medical condition characterized by recurrent seizures. More than 2 million people in the U.S. are living with epilepsy. Each year 200,000 more people in the U.S. are diagnosed with epilepsy. Of those newly diagnosed, about 20 percent are children and the rest are adults. One can develop epilepsy at any age, but it most commonly affects children and older adults.

What is a Seizure?

A seizure is a brief surge of abnormal electrical activity in the brain. It may begin when a tiny cluster of brain cells begins to send out rapid, repeated electrical discharges. This electrical firing may stay in a small area or may spread like a ripple in a pond throughout the entire brain. In other cases, the abnormal electrical activity may occur throughout the brain from the beginning.

During a seizure, the symptoms depend on the area of the brain affected by the electrical activity. Seizures vary from the mild and unnoticeable to the serious and life-threatening. Symptoms may include: staring, lip smacking, a strange sensation in the stomach, an odd taste or smell, a sense of “déjà vu”, twitching, hallucinations, inability to speak or move, confusion, loss of consciousness, falling and/or convulsions. Seizures typically last a few seconds to a few minutes. They rarely last longer than a few minutes.

TYPES OF EPILEPSY

Focal or Partial Epilepsy

Seizures which start in one part of the brain are called “partial seizures.” These may or may not spread to the rest of the brain.

The most common partial epilepsy in adults originates from the temporal lobe area of the brain and is called temporal lobe epilepsy.

Generalized Epilepsy

Seizures which start throughout the brain are called generalized seizures. People with generalized epilepsy may have brief staring spells, convulsions, or other symptoms.

What Causes Epilepsy?

Epilepsy can be caused by brain infections, head trauma, strokes, tumors, developmental abnormalities of the brain, and/or an inherited tendency for seizures. About half of the time the cause can be determined. The other half of the time, the cause cannot be determined despite the use of sophisticated testing.

Is Epilepsy Inherited?

People with epilepsy often ask “Will my children inherit epilepsy?” Some types of epilepsy appear to run in families. At this time, there is no way to know whether a person with epilepsy will pass the condition to his or her children.

Is There a Cure For Epilepsy?

At this time, there is no cure for epilepsy. Most seizures are managed or controlled by taking medication and adjusting your lifestyle.

Can Epilepsy be Prevented?

Most cases of epilepsy cannot be prevented. However, some cases of epilepsy are caused by head injuries. Head injuries can be prevented by wearing seatbelts, placing children in car seats and helmets when participating in sports such as bicycling, skateboarding, snowboarding, etc.

Good prenatal care can prevent brain damage in the developing baby that may lead to epilepsy and other neurological problems later.

Taking care of cardiovascular disease, diabetes, high blood pressure, and high cholesterol may prevent strokes that can cause epilepsy.

How is Epilepsy Diagnosed?

Epilepsy can be easily diagnosed in some patients, yet a challenge to diagnose in others. Symptoms that look like a seizure may be caused by other conditions. Determining the difference between these disorders and epilepsy may require additional testing to determine what is causing your symptoms. An accurate diagnosis of the type of epilepsy a person has is crucial for determining the most effective treatment plan.

The following methods are used to diagnose epilepsy.

Medical History	Blood Tests	EEG (Electroencephalogram)
Thorough questioning regarding one’s past medical history, including symptoms and duration of the seizures, is a crucial step to determine if a person has epilepsy. Since people who have had a seizure often do not remember what happened, reports from family members or witnesses about what occurred before, during and after the seizure are very helpful to the doctor.	Doctors often take blood tests, although they are usually normal. In general, we are looking for underlying problems that may be causing the seizures. In some cases, genetic testing can be done to help confirm the diagnosis.	The EEG (electroencephalogram) helps to diagnose the type of epilepsy and identify the location in the brain where the seizures start. The EEG provides a “snapshot” of the electrical activity of the brain. This “snapshot” can show the location in the brain where seizures start and how they progress. However, up to half of those with epilepsy may have a normal EEG recording at any given time. Sometimes the EEG may have to be repeated several times before an abnormality is seen.
Video EEG	Brain Scans (CT/MRI)	Additional Tests
Sometimes the usual 30 minute EEG does not provide enough information about the type of seizures you have. Your doctor may recommend that you be admitted to the hospital for several days of continuous EEG and video recording in an attempt to diagnose the type of seizures you have and determine the most appropriate treatment. These techniques record brain function and behavior before, during, and after seizures.	While the EEG looks at the electrical activity of the brain, MRI and CT scans look at the structure of the brain. They can detect structural damage from tumors, strokes, vascular abnormalities, etc. However, many people with epilepsy have normal brain scans.	Other tests may be needed to confirm the type of epilepsy you have. These include positron emission tomography (PET) scans, single photon emission computed tomography (SPECT) scans, neuropsychological testing, etc. Your doctor may order one or more of these tests for you, but they are not necessary for every person with epilepsy.



Managing Epilepsy

Epilepsy Medications

When a person starts taking medication for epilepsy, it is important to adjust the dose carefully to achieve the best results. People's bodies react to medications in different ways. It may take some time to find the right drug at the right dose to provide the best control of seizures while minimizing unwanted side effects. A drug that has no effect or unwanted side effects at one dose, may work very well at another dose.

Doctors will order a low dose at first, then gradually increase the dose until an effective dose is reached. In most cases, medications are successful in controlling seizures. Sometimes more than one medication is needed.

While there are risks to taking medications, there are also risks of NOT taking medications. Some seizures put people at increased risk of injury or death. Hence, our goal in managing epilepsy is "No seizures and no side effects," but not necessarily no medications.

MEDICATION DO'S & DON'TS

DO:

- * Take your medicine as directed.
- * If you see another health care provider, tell them which medications you are taking.
- * Carry a list of your medications, including doses, in your wallet.
- * Tell us if you are taking other medications, including birth control, herbs, and vitamins.
- * Take your medications on time and as directed by your doctor.
- * Use a pillbox to help you remember to take your medications as directed. Skipping a dose may result in a seizure.
- * Let us know if you have side effects from your epilepsy medications. We can often adjust your dose or change your medication to one that you can tolerate.
- * Check with your neurologist before you change your epilepsy medication doses.

DON'T:

- * Don't skip doses of your epilepsy medications.
- * Don't stop taking your epilepsy medication unless instructed to do so by your neurologist.
- * Don't change the doses of your epilepsy medications unless instructed to do so by your neurologist.
- * Don't run out of your medications. Contact your pharmacy when you have at least 1 week of medication left.
- * Don't take your medication with grapefruit juice as this can interfere with the metabolism of medications.

COMMON MEDICATION QUESTIONS

How do these medicines work?

Epilepsy medications decrease the abnormal electrical activity in the brain.

How do I know if the medication is helping?

The goal of taking epilepsy medications is to prevent seizures from occurring. For persons with difficult to control epilepsy, the goal is to make the seizures less severe and/or less frequent.

Is this medicine safe for me to take?

Although all medications have risks, there are also risks of NOT taking medications. Persons having seizures can be severely injured or die. Usually the risk of having seizures is more serious than the risks of medications. Please review section “Special Risks Associated with Epilepsy”.

Should I take the medicine with food?

We recommend that you take your medication with food. You will likely have less stomach upset and other side effects.

What side effects may occur?

Most patients can take medications without having side effects. Side effects vary for each medication and each person. In general, common side effects of epilepsy medications include feeling tired or fatigued, dizziness, problems with balance, nausea, difficulty speaking, difficulty with word finding, rash and/or osteoporosis (or thinning of the bones). Ask your doctor if there are any serious side effects which might result from your particular medication(s).

What should I do if I develop side effects?

Call our office and report the symptoms you are experiencing. Some side effects occur for a short period, others continue as long as you take the medication. Some side effects may be linked to the dose you are taking. We may instruct you to adjust your dose to improve or eliminate your symptoms.

When can I stop taking this medication?

At this time, there are no medications to cure epilepsy. Some patients will have seizures in childhood that stop as they grow older and medications may no longer be needed. Some other seizure types last a lifetime and seizure medications must not be stopped. Epilepsy medications are used to control seizures. The likelihood that a person will be able to discontinue medication varies depending on the person's age, history, and the type of epilepsy one has.

If you stop taking your anti-seizure medication, the chance of having a seizure is high for those with certain types of epilepsy, those who need multiple medications to control their seizures, and those who continue to have abnormal EEG results while on medication.

Can I take generic medications?

Generic versions are available for many antiepileptic drugs. The chemicals in generic drugs are exactly the same as

in the brand-name drugs, but they may be absorbed or processed differently in the body because of the way they are prepared. Therefore, always check with your doctor before switching to a generic version of your medication.

What happens if I stop taking my medication?

Seizures may occur when you stop taking your epilepsy medication. These seizures can be very serious and can lead to continuous seizures called “status epilepticus,” which may result in devastating complications, including coma or death.

Stopping epilepsy medication is one of the major reasons people who have been free of seizures begin having seizures again. There is also some evidence that seizures trigger changes in the brain cells, making it more difficult to treat future seizures for some patients.

What if I miss a dose?

In general, we recommend you take the missed dose as soon as possible. If it is already time to take your next dose, we do not recommend that you take a “double dose” or extra pills, as you will likely experience side effects.

Does my epilepsy medication interact with other medications I take?

This is a very important question! Be sure and check with your neurologist, pharmacist, or other health care providers before taking new medications.

Will this medication interact with my birth control pill?

Some epilepsy medications do interact with birth control pills. See section “Women & Epilepsy” for more information.

Are epilepsy medications safe to take during pregnancy?

Consult with your neurologist many months BEFORE you become pregnant if possible. There are safety measures to lower the risks of epilepsy medication to a developing fetus. See section “Women & Epilepsy” for more information.

Are there other medications I should not take?

Yes. Many over-the-counter medications, herbs, vitamins, supplements, etc. may trigger seizures in some people with epilepsy. When in doubt, check with your pharmacist or neurologist. See section “Medications to Take When You are Sick” for more information.

What about vitamins, herbs, supplements and homeopathic remedies?

Some are safe for you to take and some are not. Some may interact with your epilepsy medication and some may cause you to have a seizure. Be sure to tell us if you are taking any herbs, vitamins or over-the-counter products. When in doubt, check it out!

WHEN MEDICATIONS DON'T WORK

Resective Epilepsy Surgery

Approximately 30 percent of people with epilepsy (about 600,000 people in the United States alone) continue to have seizures despite taking their medications as directed.

When seizures are not controlled by medications, some people with partial epilepsy may benefit from epilepsy surgery. To be considered for this type of surgery, your seizures must start in only one region of the brain.

This region cannot occur in an area of important brain function, such as language, memory, and/or movement. Individuals with generalized epilepsy are usually not candidates for resective epilepsy surgery.

If patients meet these criteria, they need to be evaluated by a neurologist who specializes in epilepsy, also known as an “epileptologist.” During this lengthy evaluation, additional tests are needed to determine the safety and benefit of surgery for each person. These tests may include video EEG testing, neuropsychological testing, brain MRI, PET scan, SPECT scan, and/or a Wada test. The Wada test is an angiogram procedure done in radiology to determine whether your language and memory are located on the right or left side of your brain.

The final decision to proceed with epilepsy surgery is made by the patient and family members along with our epilepsy team (which consists of an epileptologist, neurosurgeon, neuroradiologist, neuropsychologist and others as needed).

Vagus Nerve Stimulator (VNS)

Some patients who do not qualify for resective epilepsy surgery may be a candidates to have a vagus nerve stimulator (VNS) implanted.

The VNS is a battery-powered device that is surgically implanted under the skin of the chest, much like a pacemaker, and attached to the vagus nerve in the lower neck. This device delivers short bursts of electrical energy to the brain via the vagus nerve.

The VNS rarely results in complete seizure control, but may significantly reduce seizures or seizure symptoms in up to 30 percent of individuals with epilepsy who have a VNS device. This means people with a VNS device still need to take epilepsy medication.

Side effects of the device are generally mild but may include hoarseness, ear pain, sore throat, or nausea. Adjusting the amount of stimulation can usually eliminate most side effects, although the hoarseness may persist. The VNS battery needs to be replaced about once every 5 years, which requires a minor operation.

NeuroPace

NeuroPace is a battery powered microcomputer surgically implanted under the scalp. It monitors for abnormal electrical activity in the brain and responds by delivering an electrical signal to stabilize the seizure shortly after the electrical seizure starts. The signal is delivered through one or two leads which are implanted on the brain tissue near where the seizure begins.

This device is used for focal/partial epilepsy only as it is not effective for generalized epilepsy and presently cannot be used if more than 2 different areas of seizure onset are present.

NeuroPace is not likely to completely control seizures in all patients but may reduce the severity of seizures. It is offered only when it is not possible to surgically remove the area from where the seizure starts.

Ketogenic Diet

The ketogenic diet is a special diet for some children and young adults with epilepsy. The diet is high in fat and low in carbohydrates. This unusual diet, which is not natural, causes the body to break down fats, instead of carbohydrates, to survive. This condition is called ketosis. The ketogenic diet is not easy to follow as it requires strict adherence to an unusual and limited range of foods. This diet is less effective in adults and must be monitored by a neurologist and a dietician.

Modified Ketogenic/Atkins Diet

Recent research has shown that the Modified Ketogenic/Atkins diet can reduce seizures in about 1 out of 3 adults with epilepsy. If you would like more information on this diet, please ask us for our handout on this topic. You may also visit the following websites: epilepsy.com, charlifoundation.org, and/or hopkinsneuro.org/epilepsy.



Nutrition & Healthy Bones

What About My Diet?

Eat regular meals. Skipping meals can trigger seizures in some individuals. Be sure to eat a well-balanced diet.

People over 60 years old account for 25 percent of all new cases of epilepsy. This may be related to the effects of high cholesterol, high blood pressure, smoking and/or diabetes on the blood vessels in your brain. If you have any of these conditions, discuss ways to reduce your risk of future complications from these conditions with your doctor.

What About Vitamins?

We recommend you take a multiple vitamin with minerals (or “multi-vitamin”) daily.

Are Energy Drinks Ok?

There are over 120 energy drinks available in the U.S. Some of these products contain ingredients which may trigger seizures. It is best to avoid these products.

Should I Take Calcium?

Some epilepsy medications may cause osteoporosis, or thinning of the bones. One of the key factors for building and maintaining strong bones is making sure you have an adequate intake of both calcium and vitamin D.

What Is Osteoporosis?

Osteoporosis is a disease in which the bones become weak and are more likely to break. People with osteoporosis most often break bones in the hip, spine, and wrist.

Who Gets Osteoporosis?

In the United States, 10 million people have osteoporosis. Millions more have low bone mass (called osteopenia), placing them at risk for osteoporosis and broken bones. Osteoporosis can strike at any age, but it is most common in older women. Eighty percent of the people in the United States with osteoporosis are women. One out of every two women and one in four men over age 50 will break a bone in their lifetime due to osteoporosis.

What Are the Symptoms of Osteoporosis?

Osteoporosis is called the “silent disease” because bone is lost with no signs. You may not know that you have osteoporosis until a strain, bump, or fall causes a bone to break.

How Is Osteoporosis Diagnosed?

A bone mineral density test (called a DXA) is the best way to check your bone health.

How Is Osteoporosis Treated?

Treatment for osteoporosis includes:

- * *A balanced diet rich in calcium and vitamin D*
- * *An exercise plan*
- * *A healthy lifestyle*
- * *Medications, if needed.*

What Causes Osteoporosis?

Many risk factors can lead to bone loss and osteoporosis. Some of these things you cannot change and others you can.

Risk factors you cannot change include:

Gender.

Women get osteoporosis more often than men.

Age.

The older you are, the greater your risk of osteoporosis.

Body size.

Small, thin women are at greater risk.

Ethnicity.

White and Asian women are at highest risk. Black and Hispanic women have a lower risk.

Family history.

Osteoporosis tends to run in families. If a family member has osteoporosis or breaks a bone, there is a greater chance that you will too.

Other risk factors are:

Hormones.

Low estrogen levels due to missing menstrual periods or to menopause can cause osteoporosis in women. Low testosterone levels can bring on osteoporosis in men.

Anorexia nervosa.

This eating disorder can lead to osteoporosis.

Calcium and vitamin D intake.

A diet low in calcium and vitamin D makes you more prone to bone loss.

Medication use.

Some medications, including some epilepsy medications, increase the risk of osteoporosis.

Activity level.

Lack of exercise or long-term bed rest can cause weak bones.

Smoking.

Cigarettes are bad for bones, heart, and lungs.

What About Drinking Alcohol?

Alcohol can cause seizures. In addition, it can interact with your medication. Hence, we recommend that you do not drink any alcoholic beverages.

What About Recreational Drugs?

Recreational drugs can cause seizures and other serious complications. Hence, we recommend that you do not use any recreational or street drugs.



Daily Need for Calcium and Vitamin D

Age	Calcium	Vitamin D
0 to 6 months	200 mg	400 IU
7 to 12 months	260 mg	400 IU
1 to 3 years	700 mg	600 IU
4 to 8 years	1,000 mg	600 IU
9 to 18 years	1,300 mg	600 IU
19 to 50 years	1,000 mg	600 IU
51 to 70 years	1,200 mg	600 IU
Over 70 years	1,200 mg	800 IU

Can Osteoporosis Be Prevented?

There are many steps you can take to keep your bones healthy. To keep your bones strong and slow down bone loss, you can:

- * *Eat a diet rich in calcium and vitamin D*
- * *Exercise*
- * *Do not drink alcohol in excess or smoke.*

Nutrition

A diet with enough calcium and vitamin D helps make your bones strong. Many people get less than half the calcium they need. Good sources of calcium are:

- * *Low-fat milk, yogurt, and cheese*
- * *Foods with added calcium such as orange juice, cereals, and breads*
- * *Vitamin D is needed for strong bones. Your body makes vitamin D in the skin when you are out in the sun. Some people get all the vitamin D they need from sunlight. Others need to take vitamin D pills. The chart above shows the minimum amount of calcium and vitamin D you should get each day.*

Exercise

Exercise helps your bones grow stronger. See section “Recreation & Safety” for additional information.

Healthy Lifestyle

Smoking is bad for bones as well as the heart and lungs. Also, people who drink a lot of alcohol are more prone to bone loss and broken bones due to poor diet and risk of falling.



Women & Epilepsy

The interaction of epilepsy medications and hormone balance presents a special challenge for women of all ages who have epilepsy.

Do Menstrual Periods Affect Epilepsy?

Yes, in some women. Many women report their seizures are worse around their menstrual periods. Some women ONLY have seizures at a certain time of their menstrual cycle. If you have seizures around your menstrual period, be sure and inform us about this trend. There are various strategies to try to improve your seizures.

Are Birth Control Pills Safe To Take With My Epilepsy Medications?

Some birth control pills interfere with epilepsy medications by making your epilepsy medication less effective, putting you at risk of having a seizure. Other epilepsy medications make birth control pills less effective, putting you at risk for an unplanned pregnancy. Notify us if you are starting or changing birth control pills. Other forms of hormonal birth control (such as depo provera injection and IUD) do not interfere with your epilepsy medications, but may have risks associated with them. Check with your women's health doctor regarding the risks of these products.

UC Davis Women with Epilepsy Clinic

Women with epilepsy have unique concerns pertaining to antiseizure medications and hormonal issues. We sponsor a monthly clinic staffed by UCD OB/GYN physicians as well as UCD epilepsy trained physicians accessible to women with epilepsy in our practice. The goal of this service is to achieve a tailored treatment plan for women who have questions regarding hormonal formulations, birth control medications, and/or family planning.

Importance of Taking Folic Acid/Folate

Folic acid, also called folate, is one of the B vitamins. Women need folic acid every day. It can be difficult to get your daily needs from foods, even for those who select nutritious foods daily.

Folic acid may help prevent birth defects. If a woman has enough folic acid in her body, both before and during a pregnancy, her baby is less likely to have birth defects of the brain and/or spine. Scientists are not sure how folic acid works to prevent birth defects, but they do know that it is needed for making the cells that will form a baby's brain, spine, organs, skin, and bones. The brain and spine of a fetus are formed in the first few weeks of pregnancy, often before a woman knows that she is pregnant. It is important to start taking folic acid for several months BEFORE you get pregnant and to take it throughout your pregnancy. We ask all our female patients of childbearing age to take folic acid whether or not they are planning a pregnancy.

Before You Get Pregnant

Women with epilepsy are often concerned about whether they can become pregnant and have a healthy child. Women with epilepsy have a 94 percent (or better) chance of having a normal, healthy baby. The risk of birth defects for a woman taking epilepsy medication is approximately 4 to 6 percent. The risk of birth defects for all women is between 2 to 3 percent.

There are several precautions women can take before and during pregnancy to reduce the risks associated with pregnancy and delivery. Women who are thinking about becoming pregnant should talk with their neurologist to review potential risks associated with their epilepsy and the medications they are taking. Your neurologist may advise switching to other medications prior to becoming pregnant. Whenever possible, allow several months to



properly change medications, including phasing in new medications, checking to determine when blood levels are stabilized, and ensuring seizure control is comparable to the old medication before trying to become pregnant.

Women should take a prenatal or multiple vitamin with minerals daily. You should also take folic acid (1 to 4 mg daily) for several months before becoming pregnant and throughout your pregnancy.

If you are concerned that your epilepsy may be hereditary, you may wish to consult a genetic counselor to determine what the risk to your child might be.

When You Become Pregnant

When you become pregnant, contact us as soon as possible to discuss ways to reduce the risks to your baby. Take your prenatal vitamin and folic acid daily. Continue taking your epilepsy medication as prescribed to reduce your chances of having a seizure. Seizures during pregnancy can harm the developing baby or lead to miscarriage, particularly if the seizures are severe.

Specific blood tests and high-level ultrasound tests are done during pregnancy to ensure your baby is developing normally. An amniocentesis procedure may also be used to diagnose potential birth defects.

Women with epilepsy sometimes experience a change in their seizure frequency during pregnancy, even if they do not change medications. About one third of women have fewer seizures while they are pregnant, another one third will have their same seizure pattern, and one third will have an increase in their seizures. We need to see you in clinic frequently throughout your pregnancy. Your medication dose may need to be changed and you may require blood tests more frequently during pregnancy and shortly after you deliver.

As with all women who are pregnant, get early prenatal care and plenty of sleep (to avoid seizures caused by sleep deprivation). Be sure to avoid tobacco, caffeine, alcohol, and illegal drugs. And lastly, try to avoid excessive stress!

What to Expect During Labor

Labor and delivery usually proceed normally for women with epilepsy, although there is a slightly increased risk of hemorrhage, eclampsia, premature labor, and cesarean delivery. Doctors can administer antiepileptic drugs intravenously and monitor blood levels of anticonvulsant medication during labor to reduce the risk of experiencing a seizure.

Your Baby's Health

Babies sometimes have symptoms of withdrawal from the mother's seizure medication after they are born, but these problems wear off in a few weeks or months and usually do not cause serious or long-term effects.

Breastfeeding Your Baby

If you are planning on breastfeeding your baby, discuss your epilepsy medications with your baby's pediatrician. While epilepsy medications are passed to the baby via breast milk, the benefits of nursing your baby usually outweigh the risks to your baby. Only small amounts of epilepsy medications are secreted in breast milk. This is usually not enough to harm the baby and is much less than the baby was exposed to in the womb. On rare occasions, the baby may become excessively drowsy or feed poorly. These problems should be closely monitored by your baby's pediatrician.

Helping Others & Yourself in the Future

To increase doctors' understanding of how different epilepsy medications affect pregnancy and the chances of having a healthy baby, Massachusetts General Hospital began a nationwide registry for women who take antiepileptic drugs while pregnant. Women who enroll in this program are given educational materials on pre-conception planning and perinatal care and are asked to provide information about the health of their children (this information is kept confidential). You can contact this registry directly at 1-888-233-2334 or www.massgeneral.org/aed/

Reducing Stress

Seizures can be triggered by physical stressors (such as sleep deprivation, illness, drugs and/or alcohol) as well as by emotional stressors. Some people find their seizures are worsened by flashing lights, video games, computer screens, heat, cold, dehydration, skipped meals, skipped medications, etc. Avoid the things which trigger your seizures. Keeping a seizure diary may help you monitor your progress.

Other methods to reduce stress include exercise, yoga, meditation, laughing, etc. If you need help reducing your stress, consult a counselor to develop a plan suitable to your individual needs.

Exercise increases blood flow to the brain. It reduces stress as it causes your brain to release endorphins. Endorphins are natural chemicals similar to powerful pain medications. See section "Recreation & Safety" for additional information on exercising.

What About Sleep?

Sleep is very good for your brain! Not enough sleep or changes in your sleep patterns can irritate brain cells. Try to maintain a regular bedtime and wake up at the same time each day. Get plenty of sleep - at least 8 hours per night.





Recreation & Safety

There is some evidence that regular exercise may improve seizure control in some people. Sports are often such a positive factor in life that it is best for the person to participate. However, the risk of seizures does impact people's recreational choices. Therefore, persons with epilepsy should take appropriate safety precautions.

What Precautions Should I Take When Exercising?

Common sense safety precautions apply to all persons participating in sports: Wear a properly fitted protective helmet when bicycling, skateboarding, snowboarding, skiing or rollerblading. Take steps to avoid sports-related problems such as dehydration, overexertion, and low blood sugar, as these problems can increase the risk of seizures.

What Exercises Are Best?

Walking (with another adult) or participating in yoga or other floor exercises are generally safest for most people with epilepsy.

Are There Activities I Should Avoid?

Although leading a normal life is encouraged, activities should be avoided that present special hazards to persons who may have a seizure during the activity. Do not do an activity alone if you may experience injury if you were to have a seizure while doing the activity. This would include activities such as swimming, bathing, showering, sitting in a hot tub, operating heavy machinery, or working at heights.

You should never swim alone, whether you have epilepsy or not. Be sure to have someone with you who is familiar with your seizures and can get you safely out of the water if you should experience a seizure.

Persons with epilepsy should not participate in sports such as rock climbing, waterskiing, skydiving, bungee jumping, scuba diving or motor racing where a moment's inattention could lead to injury or death.

Driving & Epilepsy

“Can I drive?” is a common question from patients with epilepsy. The ability (and inability) to drive greatly affects one’s independence, employment, childcare, economic status, etc. in this day and age.

Driving restrictions vary in each state. In the state of California, physicians are required by law to inform the Public Health Department when a patient has lapses of consciousness.

In California, the Department of Motor Vehicles (DMV) safety officers determine the outcome of one’s driver’s license when one has lapses of consciousness from various conditions. State officials are trying to ensure your safety as well as the safety of other drivers and pedestrians when restrictions are imposed.

The DMV also determines when a driver’s license will be reinstated based on the period of time without a seizure (the waiting period varies from a few months to longer).

If you have DMV paperwork to be submitted, please contact our office. You may or may not need an appointment to have this completed.

Emotions & Epilepsy

Individuals may feel a range of emotions when they are told they have epilepsy. One may feel grief, anger, loss, and/or depressed. Some people with epilepsy have an increased risk of low self-esteem, depression, and suicide. Many people with epilepsy also live with the fear that they will have another seizure.

It is not uncommon for people with epilepsy, especially children, to develop behavioral and emotional problems. Sometimes these problems are caused by embarrassment or frustration associated with seizures. Other problems may result from bullying, teasing, or avoidance in school and other social settings. Sometimes behavioral problems may result from the same injury to the brain which caused seizures to develop.

Counseling services can help patients and families cope with epilepsy in a positive manner. Epilepsy support groups also can provide a way for people with epilepsy and their family members to share their experiences, frustrations, and tips for coping with the disorder.

Symptoms of depression can include:

- * *Sadness*
- * *Loss of interest or pleasure in activities you used to enjoy*
- * *Change in weight*
- * *Difficulty sleeping or oversleeping*
- * *Loss of energy*
- * *Feelings of worthlessness*
- * *Thoughts of death or suicide*

If you are feeling depressed, seek help. Contact your local mental health department. Discuss your feelings with either your primary care physician or neurologist. If you or your family member is suicidal, call your local suicide hotline or 911.

Although most people with epilepsy lead full lives, they are at special risk for two life-threatening conditions: status epilepticus and sudden unexplained death in epilepsy (SUDEP).

Status Epilepticus

Status epilepticus is a potentially life-threatening condition in which a person either has a prolonged seizure or does not fully regain consciousness between recurrent seizures. People in status epilepticus may have severe convulsive seizures, or they may have repeated or prolonged non-convulsive seizures. They may appear confused or agitated for longer than usual after their seizures. While this type of episode may not seem as severe as ongoing convulsive seizures, it should still be treated as an emergency.

It is difficult to define the exact amount of time when a seizure turns into status epilepticus. In general, most doctors agree that any seizure lasting longer than 5 minutes should be treated as though it may be status epilepticus.

Each year in the United States, 195,000 people will experience status epilepticus and 42,000 will die as a result of it. While people with epilepsy are at an increased risk for status epilepticus, people without epilepsy are also at risk for this condition. About 60 percent of people presenting with status epilepticus have never had a seizure before. These cases may be caused by tumors, trauma, or other brain conditions.

While most seizures do not require emergency medical treatment, someone with a prolonged seizure lasting more than 5 minutes may be in status epilepticus. If this occurs, call 911. The person should be taken to an emergency room for evaluation. It is important to treat a person with status epilepticus as soon as possible. One study showed that 80 percent of people in status epilepticus who received medical attention within 30 minutes of seizure onset eventually stopped having seizures, whereas only 40 percent recovered if 2 hours had passed before they received medication.

Sudden Unexplained Death in Epilepsy (SUDEP)

“For reasons that are poorly understood, people with epilepsy have an increased risk of dying suddenly for no discernible reason. This condition, called ‘sudden unexplained death,’ can occur in people without epilepsy, but epilepsy increases the risk about two-fold. Researchers do not know why death occurs. One study suggested that use of more than two anticonvulsant drugs may be a risk factor. However, it is not clear whether the use of multiple drugs causes the sudden death, or whether people who use multiple anticonvulsants have a greater risk of death because they have more severe types of epilepsy.”

Source: National Institute of Neurological Disorders & Stroke (NINDS)



Medications To Take When You Are Sick

Some common over-the-counter (OTC) products, including cold, flu, cough, allergy, sleep, and diet medications may contain ingredients which may trigger seizures and should not be taken by people with epilepsy. These ingredients are sold under many different brand names so read labels carefully before buying products. Many herbs can trigger seizures or interact with epilepsy medications. Check with your neurologist or pharmacist before purchasing over the counter products, including herbs and vitamins.

The Following Are Generally Safe For People With Epilepsy:

Aches & Pains

- * Plain Tylenol (acetaminophen)
- * Plain Motrin (ibuprofen)

Cold & Flu Care

- * "Coricidin HBP" products
- * Dextromethorphan
- * Guaifenesin
- * Acetaminophen
- * Ibuprofen
- * Echinacea
- * Vitamin C

Vomiting & Diarrhea

- * Imodium AD
- * PeptoBismol
- * Kaopectate
- * Maalox
- * Mylanta
- * Gas-X

Allergies & Hay Fever

- * Plain Claritin (loratadine)
Allegra (fexofenidine),
Zyrtec (cetirizine).
- * Prescription nasal steroid sprays
(beclomethasone, budesonide,
flunisolide, fluticasone, mometasone,
& triamcinolone)

You Should NOT Take:

- * Pseudoephedrine or Sudafed
- * Phenylephrine
- * Feverfew
- * Ephedra
- * Oxymetazoline
- * Liquids or syrups containing alcohol
- * Claritin-D, Allegra-D
- * Over the counter nasal sprays such as Afrin, Dristan, Neosynephrine, etc.

Seizure First Aid

How To Help Someone Having A Seizure

- * Stay calm
- * Don't try to restrain him/her
- * Stay with the person
- * Speak softly, provide reassurance. Don't shake the person or shout.
- * Move items out of the way that may injure the person if he/she hits them
- * Help the person to the ground if he/she is not lying down already
- * Prevent him/her from injuring their head, place a cushion under the head for protection
- * Gently turn the person on his/her side so any fluid in the mouth can drain out
- * Never force the mouth open or put anything into the mouth. It is impossible to "swallow your tongue"
- * Loosen tight clothing around the neck
- * Note how long the seizure lasts and what symptoms occurred so you can tell a doctor or emergency personnel if necessary
- * After the seizure is over, watch the person for signs of confusion
- * Stay with the person until he or she is completely alert
- * Allow him/her to sleep if he/she is tired
- * If necessary, offer to call a taxi, a friend, or a relative to help the person get home safely

Call 911 If:

- * The person is pregnant or has diabetes
- * The seizure happened in water
- * The seizure lasts longer than 5 minutes
- * The person does not begin breathing again or does not return to consciousness soon after the seizure stops
- * Another seizure starts before the person regains consciousness
- * The person is injured during the seizure
- * This is a person's first seizure or you think it might be. If in doubt, check to see if the person has a medical identification card or jewelry stating that they have epilepsy or a seizure disorder

Source: National Institute of Neurological Disorders & Stroke (NINDS)

¿Qué debe hacer si ve a alguien teniendo una convulsión?

Si ve a alguien que está teniendo una convulsión o que ha perdido el conocimiento, ésta usted puede ayudar de la siguiente manera:

1. Voltee a la persona de lado para evitar que se asfixie con vómito o algún fluido.
2. Proteja y amortigüe la cabeza de la persona.
3. Afloje cualquier ropa apretada que tenga alrededor del cuello.
4. Mantenga abiertas las vías respiratorias de la persona. Si es necesario, agarre suavemente la mandíbula de la persona e incline su cabeza hacia atrás.
5. NO restrinja el movimiento de la persona a menos que esté en peligro.
6. NO ponga nada en la boca de la persona, ni siquiera medicina o líquidos. Esto puede causar asfixia o daños a la mandíbula, lengua o dientes de la persona. Contrario a la creencia generalizada, la gente no puede tragarse la lengua durante una convulsión o en ninguna otra situación.
7. Retire cualquier objeto punzante o sólido con el que la persona pueda golpearse durante la convulsión.
8. Tome nota de cuánto dura la convulsión y de los síntomas que se presentan para que le pueda informar al médico o al personal de emergencia si es necesario.
9. Permanezca con la persona hasta que se acabe la convulsión.

Epilepsy Resources



American Academy of Neurology

www.aan.com

American Epilepsy Society

www.aesnet.org

Epilepsy.Com/Epilepsy Foundation of America

www.epilepsy.com

Epilepsy Foundation of Northern California

www.epilepsynorcal.org

(800) 632-3532

or (925) 224-7760

Folic Acid

National Center for Birth Defects and Developmental Disabilities

www.cdc.gov/folicacid

(888) 232-5929

Medical Identification Jewelry

MedicAlert Foundation

www.medicalert.org

(800) 432-5378

American Medical ID

www.AmericanMedical-ID.com

(800) 363-5985

National Library of Medicine

www.nlm.nih.gov/medlineplus/epilepsy.html

NeuroPace

www.NeuroPace.com

Ketogenic/Modified Ketogenic dietary info

www.Charliefoundation.org

www.Hopkinsneuro.org/epilepsy

NINDS — National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov

Nutrition.gov

A service of the US Dept. of Agriculture, providing easy, online access to government information on food & human nutrition for consumers

www.nutrition.gov

Patient Assistance Programs

www.SimpleFill.com

(877) 386-0206

www.needymeds.com

www.rxhelpforCA.org

Partnership for Prescriptive Assistance

(888) 477-2669

Pregnancy Registry — Massachusetts General Hospital

www.massgeneral.org/aed/

(888) 233-2334

Research Web Sites

www.ninds.nih.gov/index.htm

www.centerwatch.com

www.clinicaltrials.gov

Support Groups

UC Davis Brain Tumor Support Group

Contact (916) 734-5613 for details

Epilepsy Foundation of Northern California has a number of local support groups.

Contact (800) 632-3532 or

www.epilepsynorcal.org for details.

UC Davis Health System — Comprehensive Epilepsy Program

www.ucdmc.ucdavis.edu/epilepsy/

USA.GOV

A U.S. government site that connects to pages of helpful services and information from federal, state and local government websites.

www.usa.gov

U.S. Department of Health & Human Services

www.hhs.gov

BOOK:

Epilepsy: Patient & Family Guide 2nd edition
by Dr. Orrin Devinsky, 2002.

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National Institute of Neurological Disorders and Stroke (NINDS)
www.ninds.nih.gov

“What is Osteoporosis?”

Fast Facts: An Easy-to-Read Series of Publications for the Public National Institutes of Health and Related Bone Diseases - - National Resource Center
2 AMS Circle
Bethesda, MD 20892-3676
800-624-BONE
www.niams.nih.gov/bone

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EPILEPSY

Managing the Details

COMPREHENSIVE EPILEPSY PROGRAM



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