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Seizures entail some risk, as does the treatment or prevention of seizures. You should be aware of these risks, so that you can minimize them. If you wish to talk to someone about seizure safety, please contact your medical care team, since advice should come from someone who knows you.

Driving

Every State restricts driving in people with seizures. States typically require that you be seizure free for either 3, 6, 12 or 24 months from the date of the seizure, depending on circumstances and doctor's recommendations. The Department of Motor Vehicles (DMV), not the doctor, makes the decision on driving in most states. Exceptions can be made for seizures that do not affect mental condition and ability to control a car, or that occur 100% during sleep. Longer restrictions may apply for commercial driving. The DMV sometimes requires a road test and a fee to reinstate the license after a medical suspension. California, Nevada, Oregon, Pennsylvania, Delaware and New Jersey laws require that medical personnel report a diagnosis of epilepsy to the State authorities, although it is not usually required to report every seizure after initial reporting. The patient also has a personal legal obligation to report seizures to the DMV. We recommend:

- Do not drive if you are having seizures that would be dangerous on the road.
- Be honest with your doctor about your seizures. Safety comes first!
- Be honest with the DMV (use their driving form). It may protect you legally if problems later occur.

Water Safety

You could drown during a seizure that occurs in water. Use the buddy system for swimming. Let the buddy know that you have seizures. Take showers instead of baths. If seizures are frequent, buy a plastic shower chair and a flexible water hose.

Burn safety

If you have uncontrolled seizures, be very careful around heat or flames. Cook on the back burner - you are less likely to lean on the burner or turn over the soup during a seizure. Don't smoke, which is good advice for other reasons as well. Set the maximum house hot water temperature to 110 degrees Fahrenheit. Put guards on open fireplaces, wood stoves or radiators.

Heights

Occasional use of ladders and going up and down stairs is a reasonable risk. If your seizures are not in control, then do not work on ladders or unprotected heights for more than brief minutes. If you fall with some of your seizures, then fall-proof your environment. Put in carpets, cover sharp corners, and consider wearing a protective helmet in some circumstances.

Equipment and Power Tools

Cutting, chopping and drilling equipment should have safety guards to avoid inadvertent injury; otherwise, do not use it if your seizures are not fully controlled. Do not use mowers lacking automatic stop switches. Do not use chain saws.

Child Care Safety

If you have uncontrolled seizures, do not carry your child in your arms, but use one of the slings/papooses. Change the baby on the floor. Do not bathe the baby in water deep enough for the mouth to be underwater. Breastfeeding is usually considered beneficial, even though small amounts of seizure medicines come out in the breast milk.

Sudden Unexplained Death in Epilepsy (SUDEP)

It is rare for people to die from a seizure, but it can happen. One way is trauma or a car crash from a seizure. Another is the poorly understood condition called sudden unexplained death in epilepsy (SUDEP). We think this is most likely due to heart arrhythmias (irregular beats) or breathing problems caused by a seizure, but the mechanism is debated. For people with uncontrolled seizures we recommend:

- Do not suddenly stop your seizure medication, since this can be a risk factor for SUDEP.
- Do not be overly worried about SUDEP. It is tragic when it happens, but it is uncommon and there are currently no preventive measures other than working toward the best seizure control.

Medication Side Effects

To be approved for prescription use, seizure medicines must pass strict safety testing. Nevertheless, they all have side effects, some of which are potentially serious or even lethal. The risks of medications must be balanced against the risks of seizures. A full discussion of possible medicine side effects is not possible here, but we recommend:

- Know the main side effects of your seizure medicines. Your doctor is the best source for individual information. Web sites such as *epilepsy.com* or *epilepsyfoundation.org* or the website of the drug manufacturer have good information.
- The package insert provided with your prescription lists full information on side effects, but most of these will never occur in an individual. Let the package insert inform you, but not scare you. Be aware that some side effects occur from drug interactions among all your medications. Interactions can involve prescription medicines, over-the-counter medicines, herbal remedies and even some foods. Grapefruit juice is an example of a seemingly benign food that can raise levels of carbamazepine or other drugs.
- Generic medications are less expensive, but may not produce the same blood levels as do brand name drugs or even other generics. Insurance plans and pharmacies sometimes switch to generics without patient or doctor approval. Be cautious if you are switching or being switched to generics. It may work out fine (and it often is a lot less expensive), but a blood test to check levels might be useful.

Seizure medicines and suicide

Seizure medicines have long been known to help some people with depression, but also to make others worse. The FDA recently took a look at their database of clinical studies of people taking epilepsy medicines. Their finding was 4 suicides in 27,863 patients taking epilepsy medicines, versus none in patients taking placebo (an inactive pill). They reported 105 people of the 27,863 who did not commit suicide, but had thoughts of suicide. Combined, the risk for suicidal thoughts and behavior was about 0.4% (1 in 250) for those taking epilepsy medications and 0.2% (1 in 500) for those given placebos.

This is important information because doctors and patients need to know the possible side effects of medicines. But it needs to be put in perspective and certainly is no reason for panic. The 4 suicides in 27,863 is a very small percentage, and it is impossible to be sure the epilepsy drugs were the cause. Depression occurs in about 10% or more of people with epilepsy, even independent of medications. We recommend the following.

- Do not stop your seizure medicine. It could be dangerous.
- If you have symptoms of depression, such as crying and low mood, please discuss them at your clinic visits, so a decision can be made about whether antidepressant medication or referral to a psychotherapist would be useful.
- If you are thinking seriously about suicide, call your medical providers immediately, or call 911.
- For most people, this FDA warning is just something to know, but not a reason to change medicines.

Carbamazepine in Asians and Rash Risk

Carbamazepine (Tegretol, Carbatrol) can cause an allergic rash in susceptible individuals. Sometimes this rash becomes severe, with swelling of the mucous membranes around mouth, eyes or genitals, or blistering of the skin. In these cases, the rash is called the Stevens-Johnson syndrome (SJS). Recent research shows that people of Asian descent have a higher risk for SJS from carbamazepine. Risk is increased with a genetic marker on blood cells called HLA-B*1502, which can be tested for in a blood test. About 15% of people from China, Taiwan, Philippines, Malaysia or Indonesia have this marker, versus 3% in people from India and 1% in people from Japan or Korea. People of Asian descent can be screened before starting carbamazepine. If someone has been on carbamazepine for 3 months already, there is said to be little risk of SJS. Further studies might indicate a similar situation for other antiepileptic drugs - we do not yet know. We recommend the following.

- If starting carbamazepine and you are of Asian descent, raise this issue with your doctor, and you and your doctor will decide what to do.
- If you have been taking carbamazepine for at least 3 months, there is no need to worry.
- Do not suddenly stop your seizure medicines.

Folic acid to protect from birth defects

Seizure medications can increase the risk of birth defects from a baseline risk of about 2% to a risk in the range of 4-15%. One of the common types of birth defects is a malformed lower spinal column (spinal bifida), potentially resulting in walking and bowel-bladder problems. The vitamin folic acid (also called folate) can decrease this risk in a general population of childbearing women. We do not have studies proving benefit specifically in women taking epilepsy medicines, but we think it reasonable to give folic acid to women with epilepsy who might become pregnant. It is best for folic acid to be in the woman's system from the start of pregnancy, which means taking it all the time. From 0.4 - 4 mg per day in a single daily dose is the usual range. An over-the-counter multiple vitamin usually has 0.4 mg (400 micrograms) of folate. Doses of 1 mg and over require a prescription. Side effects are rare, but can include stomach upset or concentration problems. We recommend:

- Do not stop your seizure medications because of this issue.
- If you might become pregnant and you are taking seizure medicines, discuss taking folic acid with your medical team.

Birth control pills

Some seizure medicines lower effectiveness of birth control pills, which can result in unexpected pregnancy. These medicines include phenytoin (Dilantin), carbamazepine (Tegretol, Carbatrol), oxcarbazepine (Trileptal), phenobarbital and primidone (Mysoline), and rarely lamotrigine (Lamictal) and topiramate (Topamax) in high doses. The negative effect of seizure medicines on birth control pills is more likely with low-dose birth control pills: those containing less than the equivalent of 50 micrograms of ethinyl estradiol. We recommend:

- Do not stop your seizure medicines or your birth control pill because of this issue.
- If you are taking birth control pills and seizure medicines, confer with your neurologist, gynecologist or primary care doctor to make sure the dose of the BCP is adequate.

Bone health

Several of the older antiseizure medications may cause thinning of bones with long-term use, leading to broken bones later in life. This is most problematic with phenytoin (Dilantin), but may occur with carbamazepine (Tegretol, Carbatrol), phenobarbital, primidone (Mysoline) and possibly valproate/valproic acid (Depakote, Depakene). This is a larger concern for women in mid-life or older, but it also can be an issue for men and younger women.

- This potential problem is not an emergency and occurs over months to years; do not stop your seizure medication without discussing your concerns with your doctor.
- Calcium, vitamin D3 supplementation and regular exercise may be helpful to maintain bone health. Your doctor may recommend other medications for bone health as well.
- Periodic bone density screening may be helpful to show existence or progression of bone thinning.

Recreation

If having a seizure during a recreational activity would cause you significant harm, then do not do the activity. Use common sense. Confer with your medical team for individual restrictions. As a general guideline for starting discussion with your medical team, we recommend:

- Low-risk recreation usually can be done by most people with seizures, even if the seizures are not in control. These include walking, running, bowling, golf, baseball, basketball, soccer, volleyball, swimming with the buddy system, weight training with machines or spotters, elliptical trainers, treadmills with spotters. Confirm this with your medical care team.
- You should be able to go at least 3 months without a seizure to participate in medium-risk activities, but confirm this interval with your doctor. These include football, hockey, ice skating, bike racing, gymnastics, horseback riding and boating.
- You should be seizure free for more than a year to perform high-risk activities, although some doctors recommend not ever engaging in high-risk recreational activities if you have epilepsy. Ask your medical team whether it is safe to engage in high-risk recreation. High-risk activities include hang gliding, motor sports, skiing, competitive skateboarding, mountain or rock climbing and SCUBA diving.

And remember: safety first! Prevention of injury is better than treatment.