

SEIZURES AND TEENS: The Practical Aspects of Managing Seizure Medications

By Patricia Osborne Shafer RN, MN, Epilepsy Nurse Specialist,
Beth Israel Deaconess Medical Center, Boston, Massachusetts

Introduction: Medications are the primary treatment for epilepsy, yet many teens and their families have problems managing seizure medicines. Fear of side effects, difficulties remembering to take medicines and figuring out how to take them are common challenges. Unfortunately, not taking medicine as prescribed can lead to breakthrough seizures, which in turn can cause falls, injuries or seizure emergencies. Loss of seizure control can also lead to the loss of a driver's license. This article explores the practical aspects of managing medications for seizures—why they are needed, how they are selected and prescribed and how people can manage them most effectively.

What is the goal of taking seizure medicines?

Antiepileptic drug therapy (commonly referred to as AED therapy) is the mainstay of epilepsy treatment. The goal of seizure medicines is to eliminate seizures without causing side effects. This usually requires a delicate balancing act of finding the right medicine(s) at the right dosage that will control seizures with the least amount of side effects. While the majority of people with epilepsy get good seizure control with medicines, about 25% do not achieve seizure freedom from AEDs.

How do AEDs work?

Seizure medicines stabilize the flow of substances in and out of brain cells and affect the signaling between brain cells. These

actions can help prevent or limit the abnormal electrical activity that underlies seizure activity. The key is that AEDs only work to suppress seizures – they do not cure epilepsy. And they only work when taken; once the right dose of an AED is found, the same amount of medicine must be taken each day to keep a constant amount available in the bloodstream and brain at all times. If a medicine dose is changed or missed, the amount in the body will change, and it will take a number of days to stabilize again. If doses are missed repeatedly, the person won't have a steady amount of drug to control seizures. The level of drug in the bloodstream will be erratic and lead to more frequent seizures. (insert call-out here)

How long will it take for a drug to begin to work?

A drug is usually started at a low dose and gradually increased over days to weeks. If begun at too high a dose or increased too quickly, an AED may cause intolerable side effects. Once a drug reaches a stable amount in the body, adequate time is needed to know how well it will work. Adjustments in the dose may be needed if breakthrough seizures occur. Usually the dosage is increased as needed until seizures stop or the person has bothersome side effects. This daily dosage and the resulting blood level may be different from one person to the next as there is no single best dose for most medicines. Since the right dose will vary for each person, it's impor-

tant that teens and their families have a good working relationship with their health care team to help monitor how the teen responds to the drug and make sure that the right dose is reached in as short a time as possible.

How long it will take to find this best dose can be affected by how the body metabolizes or breaks down each medicine. Those that are broken down quickly can reach a stable amount faster than those that last a long time in the system. Also, medicines that are broken down by certain liver enzymes are more likely to interact with other medicines. Many of the older seizure medicines (such as phenytoin, carbamazepine, phenobarbital, primidone and valproate) fall into this group of drugs. Some of the newer AEDs (such as gabapentin, levetiracetam, topiramate or zonisamide) are cleared from the body primarily by the kidneys and tend to have less drug interactions. Drug interactions are important to understand as they may affect what drug is selected, how it is prescribed and how it is monitored.

How often do I need to take seizure medicine?

How often a medicine is taken depends on many factors, including how long the drug lasts in the body, whether it is taken alone or with other medicines, the total daily dose and whether and when side effects occur. Many of the older medicines must be taken three or more times a day to keep an even amount in the body or to avoid side effects. Luckily, longer acting versions of the older drugs have been recently developed, allowing them to be taken once or twice a day (Table 1). Usually, the less often a person needs to take a medicine the easier it is to remember.

How do I know which medicine is best for me?

The 'good news' is that there are many different drugs from which to choose to control seizures. But there is no single 'best' drug for every teen. Some drugs are better

for certain seizure types, and others work well against many different seizure types or epilepsy syndromes. The effectiveness of a medicine is usually described in terms of how well it works in groups of people with epilepsy. The frustrating part is that there is no way in advance to know how a particular drug will work for a specific person—whether or not seizures will be controlled and to what degree.

How do I know which drug to try?

The first step is to make sure that the diagnosis and seizure type are known, then appropriate options can be explored. How well a drug may be tolerated and how quickly a drug can be started are important factors to consider. For example, a teen who needs to start a medicine quickly may do better with a drug that can be raised to an effective dose relatively easily as compared to one that may require weeks to months to reach an appropriate dose. However, an adolescent who is concerned about possible side effects may choose to try a medicine that has fewer side effects when started slowly.

What happens if the first drug doesn't work?

If the first drug doesn't work, it's important to first ask why. Was the drug tried at a high enough dose? Was the medicine taken regularly or did missed doses lead to breakthrough seizures? Sometimes other factors can trigger seizures regardless of taking medicine. Tracking seizures on calendars along with other possible triggers can help identify if other factors should be looked at before changing drugs. For example, if a teen is having difficulty remembering to take medicines, ways to make it easier to remember should be tried first.

If seizures persist, other medicines are available. Most often AEDs are thought to work best when tried one at a time. However, many people do best on a combination of seizure medicines. Whatever drug is chosen, adequate time needs to be given to monitor how well the therapy may work and how the person is tolerating the drug. If at least two or three carefully tried trials of appropriate seizure medicines still fail to control seizures, a doctor who specializes in treating adoles-

Try this experiment.

Punch a hole in the bottom of a paper cup. Pour water into the cup. If you stop pouring water into the cup, the water will run out the hole in the bottom until the cup is empty. If you pour more water in than comes out the bottom, the level of water will rise too high. If you pour water in as fast as the water runs out of the hole in the bottom, a constant amount of water will stay in the cup. You have now reached a 'steady state'! The same scenario will occur when medicines are not taken regularly—if not enough is taken, the amount in your body will drop too low. If too much is taken, the amount will build up too high.

cents with seizures should be consulted to confirm the diagnosis and consider other options, including investigational medicines, surgery, dietary therapies or devices.

Can I ever come off medicine?

Coming off medicine will depend on how long a person has been seizure free, the cause of seizures, a person's age and the likelihood of having more seizures. Children and teenagers who do not have any known injury to the brain, have a normal EEG and neurological examination and have been seizure-free on medicine for two to five years are most likely to do well coming off AED therapy. Even so, there are no guarantees. Teenagers with seizures that are associated with other neurological problems or who have an EEG that shows a susceptibility to more seizures are less likely to be able to come off medicines without recurrence of seizures.

If coming off AEDs is recommended, parents and teens must consider the practical ramifications of stopping medicines. The teen will most likely be restricted from driving during a medicine change. If seizures recur off the drug, the teen will need to refrain from driving until seizure control has been reestablished for a period of time specified by local driving regulations. Thus, the ability to get around with public transportation or with help from others needs to be explored. Safety issues should be considered for teens who participate in certain sports or other potentially dangerous activities and for the teen living away from home. For example, make sure that teens are following safety precautions, have an emergency plan in place and teach friends, coaches or roommates seizure first aid. Encourage teens to wear medical emer-

gency identification, especially for those who are independent and more apt to be out alone (and ideally for any teen with a history of seizures!). Using common sense and talking to the doctor or nurse about safety precautions appropriate for the teen's situation is a wise idea before making any medicine change. Being prepared for any outcome can lessen anxiety and fears and, in turn, make the process of managing medicine withdrawal easier for all involved.

How do I know if the drug works?

Knowing how well a drug works is going to depend primarily on information from the teen and their family. Keeping track of the number and type of seizures, changes in what seizures look like or how 'severe' they are and in the occurrence of side effects is critical information that should be brought to all appointments so that the physician can evaluate how the teen is doing. Side effects do not occur in everyone, but if they do, knowing what happened, when and for how long can help the doctor tell if they are related to medicine, seizures or some other problem.

What side effects are likely to occur?

While any medicine has the potential to cause side effects, some are more problematic than others. Also, the type of side effects that may occur can vary from one drug to another and from one person to another. For example, some drugs can cause problems such as dizziness, poor coordination, blurry or double vision or unsteady walking. These are usually related to the dose of medicine and can be resolved when the dose is adjusted. Allergic reactions, skin rashes or other serious problems are rare but can occur with any drug and may require stopping the drug.

More commonly, side effects may occur regardless of dose. Whether or not medicine changes are needed will depend on how these problems affect the individual. Medicines that cause fatigue, speech abnormalities, or attention or memory problems can affect how well a teen does in school, at home or socially. If possible, therefore, staying away from medicines that may affect a teen's thinking is often preferable. Some medicines can lead to vague feelings such as lightheadedness or dizziness or can cause other health problems such as swelling of the gums, excess facial or body hair, loss of appetite, nausea, weight gain or loss, thinning of the bones or hormonal problems. Mood changes may also be seen; while some medicines may lead to irritability or depressed mood, others may help stabilize mood! Knowing how to observe and track side effects and what to do about them are important steps in managing medicines.

What steps can be taken to manage side effects?

Fears of side effects often keep people from trying a medicine that could be very helpful. Before a drug is started, teens and their families should have a clear understanding of the possible risks and know steps to lessen those risks. They should also investigate factors that might predispose a person to developing side effects. People should know if or when a medicine should be stopped like when an allergic reaction or severe rash were to occur, for example. Most often a drug should never be stopped abruptly and without the doctor's advice. Seizure emergencies can occur that can be life threatening and require emergency treatment.

There may be times when a blood test is needed to check how much medicine is in a person's system and to check how the body is tolerating the drug. This can help the doctor or nurse tell if the dose of certain medicines may be too high or whether the drug should be stopped because of its effects on the body.

For non-dose related problems, changing how the medicine is taken, such as taking it after meals or at different times of day, can help lessen side effects. If a person is also taking other medicines, it's possible that side effects could be due to an interaction

between two drugs or how the two drugs affect the body. Understanding possible drug interactions and what to do if any occur should be part of a family's plan for medication management.

How can I make it easier to take and remember medicine?

It's very hard to remember to take any medicine on a daily basis. It's even harder to remember when doses need to be taken many times a day. Interestingly, compliance, or the ability to take medicines according to prescribed instructions, is often harder in teens with well-controlled seizures than in teens who have ongoing seizures! People may mistakenly think that they don't need the medicine any longer if their seizures are fully controlled.

Research has shown that not taking medicine correctly or missing doses can lead to seizures occurring. Problems taking medicines can be due to not remembering to take them, not understanding how to take them or not being able to afford them. Noncompliance can also be a way that a teenager acts out his feelings about having seizures. Most of the time, seizures are not visible, but the medicines are. Taking anger out on the medicine is not unusual, but unfortunately, this can lead to more seizures.

When taking medicines is a problem, teens and their families should work together with their health care providers to find a system that will work for them. Sometimes simplifying the medicine schedule helps, for example, taking fewer pills or just taking them less often. Being clear on how to take the medicines, especially when liquids or different formulations are used, is critical. Some AEDs come in special preparations that can be opened and sprinkled onto food. Others that may be used to prevent seizure emergencies may be given rectally or dissolved under the tongue. While the different ways of taking medicine are designed to be easier, they will require more detailed instructions on what to do.

There are many reminders available to make it easier to take medicines at the right time. Having a medicine chart handy is a must for everyone. Keeping pills in a pillbox helps serve as a way to check that the teen has not missed any doses. (Figure 1) This is

most helpful when multiple daily doses or multiple drugs are prescribed. Other reminders may be needed; electronic gadgets can be great for this, such as alarms on watches, cell phones, computers, or personal digital assistants. Just taking meds at the same time as some other routine, such as brushing teeth, eating meals or going to bed, helps people remember their medicine.

How do I find out more information?

Taking medicines can be scary and confusing. Lots of questions may arise, but it's usually impossible to remember everything that the doctor explains in an office visit. Taking notes and having someone else present during doctor visits can be of great help when learning how to take medicines. Leaving visits with a 'To Do List' of important information and helpful tips makes managing medicines at home a lot easier. Pharmacists can help people be aware of possible drug interactions and questions to ask the prescribing doctor. Detailed drug instruction sheets can be obtained from the doctor's office, pharmacies, and reliable online resources. For example, instruction sheets are available at [epilepsy.com](http://www.epilepsy.com/epilepsy/seizure_medicines.html) for the different AEDs (http://www.epilepsy.com/epilepsy/seizure_medicines.html) and for potential drug interactions (<http://professionals.epilepsy.com/page/doclib.html>). (Figure 2) These sheets provide general information, but since managing medicines in teens with seizures can be so individualized, it's important to review the information together with the treating doctor or her nurse and make sure that everyone knows what to expect in their particular situation.

Summary:

Medication management in epilepsy depends on a good working relationship between health care providers, teens and their families. The choice of drug and an understanding of how well the drug is working depend on clear communication between the teen, their family and the doctor. While the doctor has the expertise to prescribe a medicine, the teen and his family will need to be the experts at taking it. Learning as much as possible about each treatment and feeling confident in knowing what to do will help ensure successful medication management.