

**Prepare** before you go to your provider's office. Check off the statements that apply to you and discuss with your provider.

#### Since my last visit:

- I have had seizures.
- My seizures have changed.
- I have felt moody or blue some of the time.
- I have had problems at school or at home.
- I have made progress on my goals for managing epilepsy.
- I have missed taking some of my medicine(s).
- I have stopped or changed how I take my medicine.
- My medicine has caused side effects that bother me.

- Bring this list with you to your next provider visit.
- Bring all your medicines with you to each visit, including vitamins and supplements.



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## Your Treatment & You: Working Together to Help Manage Your Health

My Day Calendar

10:00 am - Doctor Appt.

3:00 pm - Soccer game

7:00 pm - School dance!

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## Because it's important to know as much as you can.

This booklet is designed to help you understand epilepsy and the things you can do every day to help manage it.

As always, talk to your heathcare provider for more information.



Taking your medicine as directed is one of the most important things you can do. If you're like most people, this may be easier said than done. For more help and information, contact one or more of these epilepsy resources:

### For Teens With Epilepsy

**Epilepsy Foundation** www.epilepsyfoundation.org 800-332-1000

To find information for teens: Click on "Learn," then go to the bottom of the page and select "Age Groups," then select "For Youth."

### For Parents of Teens With Epilepsy

**Centers for Disease Control and Prevention (CDC)** *You Are Not Alone: Toolkit for Parents of Teens with Epilepsy* www.cdc.gov/Epilepsy/toolkit/index.htm

It's a good idea to tell people you are close to that you have epilepsy. If you have a seizure while you are with them, they can help you.

The resources listed above are administered by independent third parties not affiliated with or endorsed by GSK. GSK is not responsible for the content of these resources.



## **Epilepsy Support**— **Where Can I Go for Help?**

## **(**Nobody understands. I don't know anybody else with epílepsy.**)**

- You can talk to other people your age with epilepsy. Ask your provider about a support group for people with epilepsy.
- If your parents agree, you can join an online chat group for teens with epilepsy.

#### If you are scared to tell people you have epilepsy:

- Talk to your parents or your provider about this.
- Your parents or provider can help you decide who to tell and what you should tell them.

#### If you are worried you won't be able to drive:

- You may be able to drive if your seizures are well controlled. States have different driving rules for people with epilepsy. Check with your provider or Division of Motor Vehicles (DMV) for the rules in your state.
- You can also visit the Epilepsy Foundation Web site to learn more: www.epilepsyfoundation.org.

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## Epilepsy—What Is It?

### **CC** I'm scared I'll have a seizure at school. **)**

It's normal to worry about having seizures, especially at school. To help you deal with your feelings and help you manage your seizures, learn more about epilepsy and what you can do to help manage it.

#### What is epilepsy?

Epilepsy is a condition that makes people more likely to have seizures. A seizure is a sudden burst of electrical signals in the brain. This sudden electrical activity can change the way you act, feel and move. It can make some people pass out.

#### What does a seizure feel like?

The symptoms of a seizure depend on where in the brain it occurs. There are two main kinds of seizures:

- Focal seizures occur in just one part of the brain. They may cause unusual sensations or repeated movements and twitches. They may also cause a person to pass out.
- Generalized seizures start and spread in both sides of the brain. One type (tonic-clonic) can cause a person to become stiff, pass out, and shake all over.





#### **Questions to Ask My Provider or Pharmacist:**

- What is the name of the medicine and how will it help me?
- How and when do I take the medicine, and for how long?
- What do I do if I miss a dose?
- What are the possible side effects? What should I do if they occur?
- Will this medicine affect my other medicines (including over-the-counter) for epilepsy or for other conditions?
- What are my limitations at school or at home?
- When and how do I refill my prescription?



## My Healthcare Provider Visits— How Can I Get Ready?

You and your provider are a team in managing your epilepsy. Talk openly and honestly with your provider.

### ((It's not easy to talk with my doctor.))

- All questions are important. Do not be shy about talking to your provider—even about how epilepsy affects your social life and school life.
- Learn what can bring on your seizures.
- Ask your parents or another family member to join you for provider visits. They can take notes.

## *If you have trouble understanding or remembering what your provider says:*

- Ask your provider to repeat anything you don't understand.
- Ask for written information about epilepsy and your medicine. Your provider may have information written for teens.
- Ask your provider or pharmacist to help you answer the questions on the next page.

To learn more about what may be getting in the way of taking your medicines, go to www.HealthCoach4Me.com.

## **((** why did I get epilepsy?**)**

One in 100 teenagers has epilepsy. Anyone, at any age, can get epilepsy. You cannot "catch" epilepsy from someone else. Most of the time, the cause isn't known.

### You can help manage your epilepsy

Epilepsy cannot be cured. But there are medicines that can help you have seizures less often. To help manage your epilepsy:



**Take** your medicine as directed by your provider.



**Keep** all your provider appointments. Talk openly and honestly.



Learn what brings on your seizures, such as:

- Missing a dose of medicine
- Lack of sleep
- Illness or fever
- Stress
- Too much alcohol
- Abusing drugs
- Flashing lights
- Hormonal changes in girls



**Plan** ahead to try to avoid the things that bring on your seizures.

The goal of epilepsy treatment is to reduce seizures with the fewest possible side effects. Use a goal checklist and talk to your healthcare provider.



## My Epilepsy Goals—What Are They?

You are the most important person in managing your epilepsy. Talk with your provider to help you choose one or more goals you are ready to work on now. Place a check next to your goals below.

## Goal 1

#### Provider Visits

I will keep my provider appointments even when I feel fine.

- I will talk to my parents and my provider about my seizures.
- I will ask questions when I do not understand something.
- I will\_\_\_\_\_

#### Medicines

- I will take my epilepsy medicine(s) as directed by my provider.
- I will tell my parents and call my provider if I have problems.
  - I will not stop taking my medicine without first talking with my provider and my parents.
- I will \_\_\_\_\_

# Goal 3

Goal 2

#### Triggers and Daily Life

- I will try to avoid things that can bring on my seizures.
- I will keep a regular schedule. This includes eating well and getting enough sleep.
- I will ask my provider what types of exercise and sports are good and safe for me.
  - I will \_\_\_\_\_

- Enter the month and year at the top of the page.
- Number the small squares of the calendar with the days of the month.
- Use the seizure key at the bottom to enter information on the days you have had a seizure.
- Bring this calendar with you to each provider visit.



#### **Description of Seizures Key**

- 1) Unusual feelings
- 2) Unusual sensations
- 3) Repetitive movements
- 4) Aura
- 5) Dreamlike perceptions
- 6) Jerking or twitching muscles 12) Other

7) Stiffening of muscles
8) Softer than normal muscles

- 9) Convulsions
- 10) Blackout
- 11) Don't know or don't remember

For female patients only M On your period

Enter the appropriate number above on the days you have had a seizure.



Make a list of the things you would like to do. Take the list to your next visit, and ask your provider which activities are safe for you to do.

## Epilepsy Medicines— What Should I Know?

There are many types of epilepsy medicines. Epilepsy medicines often affect people differently. It may take some time to find the right medicines for you.

## Can I stop taking my medicine if it makes me feel worse?

- DO NOT stop taking your medicine or change the amount you are taking unless instructed to do so by your provider. Serious seizures may occur.
- Epilepsy medicines have side effects. Tell your parents and your provider about any side effects you have. Some may be signs of serious problems. Some can be managed or may go away over time.
- Keep talking to your provider. Your provider may need to prescribe a different type of medicine.

## ((1'm so busy. It's hard for me to keep track of my medicine.)

Taking one or more medicines at different times each day can be hard. The key is to create a routine that fits your life:

- Try taking your epilepsy medicine around the same time as other daily habits, such as in the morning when brushing your teeth or in the evening around dinnertime.
- Ask if your medicine should be taken with or without food. Talk to your provider about a routine.
- If you have trouble remembering to take your medicine, ask your provider if there is a medicine that you can take less often. A simpler medicine schedule may help you.

#### If you often forget to take your medicine:

- Ask your pharmacist if it is OK to use a pillbox marked with the days of the week to store your medicine. If it is OK, you can take it with you when you are away from home.
- Wear a watch. Set an alarm. Leave yourself a note on the bathroom mirror.
- Keep your epilepsy medicine in a place where you will see it every day.



## Sticking With My Medicine— What Will Work?

It can be hard for people with epilepsy to follow their treatment plan all the time. School, sports, work—they can all get in the way of taking your medicine.



Taking your epilepsy medicine as directed by your provider is one of the most important things you can do to help manage epilepsy.

## *Not taking your epilepsy medicine as directed by your provider means:*

- Your medicine may not work the way it should.
- You may have more seizures.

Use a seizure calendar to keep track of your seizures. Bring your calendar with you to each healthcare provider visit.

## **((**My seízures have stopped. Why do I need to keep taking my medicine?**)**

- Taking your medicine as instructed by your provider may be why you have not had a seizure. You need to keep taking your medicine to help reduce seizures as much as possible.
- If you skip a dose and don't have a seizure, this is not a sign that you don't need medicine anymore.

#### Give your medicine time to work for you!

- Your provider may start you off with a low dose. Over time, your provider may slowly raise the dose until it reaches a good level for you.
- Your provider may first try to manage your seizures with one medicine. But sometimes two or more medicines are needed.
- Your provider may do blood tests on a regular basis. These tests will check blood levels of your epilepsy medicines or check on your liver or kidneys.



Fill out a medicine chart with the help of your healthcare provider. It is important to discuss this chart at every visit.



## My Medicines—Am I Taking Them As Directed?

Fill out a medicine chart like the one below and talk with your provider. This may help you take the right dose at the right time. Include all medicines that you take for all reasons.

Ask your parents to help you by...

- Marking medicine refill dates on a calendar
- Listing more information in the special instructions column (like, what to do about side effects)
- Checking your medicine before leaving the pharmacy to make sure it is the medicine your provider prescribed for you. If it is not, tell the pharmacist
- Talking to your provider and asking whether it is safe for your epilepsy medicine to be changed by the pharmacist

Date Started	Name and Strength of Medicine	How Much I Take	When I Take It	l Take It For	What My Pill Looks Like	Dates to Refill Rx	Special Instructions