

# SEIZURES AND TEENS: Using Technology to Develop Seizure Preparedness

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**Teens and technology** go hand in hand. Accessing the Internet is a way of life for most adolescents. They shop, download music, play games, and do homework online. Teens even communicate differently, staying in touch by texting, messaging, chatting, or posting. The Internet is also a source of health information and care. While people should not look for individual medical advice and treatment online, the Internet can be a wonderful way to locate relevant health information, develop supports with people in similar situations, practice skills, and find resources.

The Seizures and Teens articles over the past year have highlighted many facets of epilepsy care and problems that teens with seizures and their families may face, with a focus on what they can do to manage their epilepsy and health. Some people will have concerns not addressed in this series or that may arise at a later time. Hopefully, information and skills previously learned can be applied to these new challenges and help teens and their families be prepared. This article, the last in the Seizures and Teens series, will

discuss the concept of seizure preparedness and offer examples of how teens and their parents can use the Internet to assist them in managing their epilepsy.

## What is Seizure Preparedness?

Preparedness is generally defined as a “state of full readiness or attentiveness, awareness, or vigilance.” We often hear this term in relation to emergency or disaster preparedness, but preparedness is a concept that must also be applied to our health. If we know about possible problems in advance, we can be attentive and know what to monitor. Preventive actions can be taken, and we can be prepared to act promptly if problems arise.

Applied to epilepsy, seizure preparedness is being ready or prepared to respond to seizures, prevent emergencies, manage medications and other treatments, and cope with the way epilepsy affects day-to-day life. Based on self-management concepts, seizure preparedness invites people to be informed, work together with their healthcare providers, and take charge of their lives.

## Who should be prepared?

Everyone whose life is touched by seizures should know their role in managing epilepsy. Parents of young children or preteens may be the main “managers” and will have a major role in making sure appropriate people in their child’s life are prepared. This may include teachers, school nurses, childcare workers, healthcare providers, friends, and relatives. Depending on the child’s developmental level and independence, the parent of an older teen will need to step back from being the primary manager and teach their teen how to manage their own seizures. The parent’s role will be more of a facilitator, coach, and cheerleader. This is the hardest time for parents. Watching your teen struggle as they take on new challenges can be frustrating, but it’s also rewarding to see them learn from these experiences. Teens develop a sense of resiliency and confidence as they tackle tasks such as talking to their peers about their epilepsy, making friends, learning how to handle a seizure in public, staying safe, or preventing a cluster of seizures from becoming a seizure emergency.

## What do I need to learn for seizure preparedness?

Living with epilepsy is more than just knowing your type of

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seizures or what medicine to take. People must learn how to respond to seizures in a variety of circumstances and be prepared to handle complex diagnostic tests and medical or surgical treatments. It's about knowing the "how to" of managing seizures and how to apply your healthcare provider's recommendations to your own situation. Living with seizures also means learning how to handle the way that epilepsy affects your life including your social, emotional, and physical well-being.

For example, understanding a diagnosis of epilepsy will require teens to know how to recognize a seizure, how to teach others to observe seizures, and how to use seizure calendars or diaries to monitor their responses to treatment. Treating seizures effectively will require teens to understand the practical aspects of taking seizure medicine, how to remember and take them safely, how to recognize and prevent side effects, and how to find resources for prescription coverage. Since many health and lifestyle factors can affect seizure occurrence, teens will want to know how to monitor their seizures in relation to possible triggers and how to lessen or avoid these. For teens, this can be quite difficult as a teenager's typical lifestyle is not conducive to good seizure control.

One of the most important areas for teens to learn is appropriate seizure first aid and how others should respond to their seizures. While most seizures are not emergency situations, seizures can occur too often or last too long, resulting in serious injury or harm. People need to know what may increase their chance of an emergency occurring, how to recognize and prevent emergency situations, and how others can help. This part can get very tricky. Teens don't want to be different—they want to 'fit in' and be just like everyone else. They'll need to balance their wish to keep information about their seizures private with the need to educate their friends and peers on what to do should they have a seizure in front of their peers.

### How can technology be used to learn seizure preparedness?

Most people learn about seizures from their doctors, but others know only what they have seen on television. Unfortunately, visits to the doctor's office aren't long enough to learn all that is needed, and often times, doctors and nurses aren't available to teach this information. Seizures are often represented inaccurately and too dramatically on television, leaving people feeling confused and scared. Books and pamphlets may be available, but often this isn't enough. This is where the Internet can help. When used appropriately, credible Web sites can be a wealth of information and provide tools and resources for seizure management and can supplement information obtained from your healthcare team. A major benefit to using the Internet is that it can be done when you're ready, in small steps, and doesn't require a car to get there! You can revisit sites as frequently as you want, which can be an enormous help for people with memory or attention problems. A few of the commonly used Web sites in the U.S. include *epilepsy.com*, the Epilepsy Foundation, and *Exceptional Parent* ([www.eparent.com](http://www.eparent.com)).

*Epilepsy.com*, sponsored by the Epilepsy Therapy Project, offers a broad range of information from basic to advanced levels for people with seizures, their families, and professionals. Designed for people with newly diagnosed seizures and those whose seizures resist treatment, many of their tools and resources support seizure preparedness education.

- *Seizure Preparedness* modules start by addressing seizures and seizure emergencies, treatments, and safety. Written for the person with seizures or their parent, guardian, or loved one, it takes a practical approach to managing seizures that emphasizes preparation, prevention, and teamwork. It is built-in modules or sections that you can work through one by one, or jump in and go to the areas that are of greatest concern.
- *My Resource Kit* offers forms and tools to help people observe seizures, use seizure diaries, organize questions for their healthcare team, keep track of medications, personalize a seizure action plan or tailor seizure management to specific situations such as camps, vacations, school, or work.
- *The Multimedia Center* lets you see what a seizure looks like and offers tips on seizure first aid for different seizure types. These can make teaching first aid to family, friends, or even school personnel easy and quick. The multimedia center reinforces the view that "a picture is worth a thousand words," offering Web casts on a variety of conferences and topic areas.
- *Downloadable Medicine Sheets* offer easy to read information on all the different seizure medicines with practical tips to make taking medicines easier and safer.
- *My Seizure Diary* will let teens and their families create their own seizure diary to track and record seizures and treatments over time. People can track their own data and print out reports to give to their healthcare providers at clinic visits. This reinforces the importance of taking an active role in managing your seizures.
- *My.epilepsy.com* is the way to connect and share experiences with others in similar situations. The community offers forum threads, chats, blogs and personal groups as ways to give and get critical support and learning.

*Exceptional Parent* magazine, [www.eparent.com](http://www.eparent.com), offers a wealth of information for people with disabilities of all ages, particularly children and adolescents. *EP* magazine and *EP's* Web site encourage parents to think beyond the medical disorder and find information and resources that help people cope with the consequences of epilepsy and other medical problems. Parents of teens with seizures and other disabilities may find valuable resources and equipment ideas as well as ways to help teens develop independent living skills.

The Epilepsy Foundation, [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org), is a national organization dedicated to increasing awareness of seizures and epilepsy and ensuring that people with epilepsy can participate in all life experiences. A major strength of the Epilepsy Foundation is the ability to connect people with an affiliate office that can provide services and programs tailored to local communities.

In addition to providing information on basics of seizures and

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treatment, there are detailed sections on:

- Managing the unique needs of women with epilepsy, people with mood disorders, children, and adolescents.
- Targeted programs on epilepsy for school nurses and first responders can be used for training programs and continuing education.
- Employment resources help people build job skills and find epilepsy-specific job help.
- The Foundation's advocacy network, "Speak Up, Speak Out," teaches advocacy skills that can help people make their voices heard locally and nationally.
- Living with epilepsy requires people to be aware of their legal rights and responsibilities. The Jeanne A. Carpenter Legal Defense Fund may also be able to help families with epilepsy-specific legal issues.

### **Are there any precautions I should take when using online resources?**

People should be cautious about relying on information from some online sources and should research the sites being used. The two sites listed here are well-established sites with content contributed and reviewed by medical experts. Individual medical advice should not be sought from general Web sites. It's wise for parents and teens to share the information they obtain from the Internet with their doctors and other healthcare providers. This way, the people who know your teen best can help interpret what the information means in specific situations.

When teenagers use the Internet, parents should know what sites the teen is using and test the site out first. Parents are encouraged to visit the community forums and teach their teens how to use them safely and appropriately. Young children should not use the Internet alone and are not allowed to use community forums in many instances. While most sites are open to teenagers, they should have parental permission first.

Parents should also be aware that children with photosensitive epilepsy may be more susceptible to seizures with prolonged use of computers or video games, particularly when sites or games with specific flashing patterns or frequencies are used. People who are susceptible to flashing lights should talk to their doctor first about computer use and discuss ways to prevent problems from arising.

### **Summary**

Seizures and epilepsy will be a way of life for many parents and teenagers. Technological advances are changing the way we learn about epilepsy and how we connect and communicate with others. While medical care is focused on stopping seizures, we must also work to prevent other health problems and improve the life and experiences of families and teens. We hope that these seizure preparedness resources will help parents and teens accomplish these goals. •

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