



News and views for those living with epilepsy

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In this and upcoming issues, you can expect to read

- Helpful tips about adjusting to the changing seasons
- Advice from a medical specialist on common concerns related to epilepsy
- Interviews with people who are living with epilepsy
- Details about useful sites on the Internet
- Information about historical figures and famous personalities who have lived with epilepsy

Each article in the newsletter is prepared with you in mind. We hope you enjoy our first issue.

WELCOME TO LIVE, LEARN, AND SHARE



An introduction to the new SHARE newsletter

Greetings to our readers! We're excited to bring you the first issue of Live, Learn, and SHARE, the **SHARE** (Support, Help And Resources for Epilepsy) newsletter.

This newsletter has been designed to provide helpful information, tips, and support to all those living with epilepsy—including those who have been diagnosed with this condition, and those who are caring for relatives or friends with epilepsy.



LIVING WITH EPILEPSY: WINTERTIME CONCERNS

How does winter weather affect people living with epilepsy?

Winter is a season that often causes lifestyle changes for everyone—and if you're living with epilepsy, it may mean you have to take a little extra care.

For example, winter means the continuation of the cold and flu season that started in the fall. If you develop cold or flu symptoms and need to take a medication, you'll need to ask your neurologist or nurse if that medication will affect your seizures, or even cause them. It doesn't matter if you get your medication over-the-counter from a pharmacy or by prescription from a doctor; either way, that medication can interact with your seizure medication, causing side effects or putting you at risk for seizures. Also, medications for other conditions may affect seizure medications so that they don't work as well in fighting off seizures. That's why it's important to speak with your doctor, so he or she can adjust your seizure medication or new medicine if necessary to treat your cold or flu symptoms.

Of course, winter weather may cause hazardous outdoor conditions in many parts of the country. Snow and ice can be dangerous to anyone while they're walking or driving, whether or not they have epilepsy. But when you're living with epilepsy, you may need to give special thought to what may happen if a seizure occurs during a wintertime activity. If you're skiing or hiking, make sure you have a companion with you so that person can get help in case you're in a remote area. Also, be sure to wear the appropriate safety gear to prevent head injuries or reduce the risk of falling while skiing or taking part in another winter sport. While skiing, this means wearing a helmet while you're on the slopes, and using a safety strap and hook when riding the ski lift.

Yet winter weather can cause safety concerns while you're indoors, too. Be careful to avoid space heaters that may tip over. If you have a fireplace, install guards around it, and close the screens while you're burning a fire. Don't light any fires if you're alone, and do not carry hot fireplace ashes through the house.

Finally, you or your child might be tempted to enjoy certain comfort foods that contain a lot of carbohydrates, such as sugary baked goods, during the winter. However, those who are on a ketogenic diet of high fats and low carbohydrates need to make sure they stick to that diet, so it's best to avoid having cookies or cakes around the house. Even a small amount of carbohydrates could affect the metabolism of someone on a ketogenic diet and cause a seizure.

With a little planning and forethought, winter can be a fun time for all. By keeping the above tips in mind, you can reduce the risk of injury and enjoy the season at the same time!



*“STRENGTH DOES NOT COME FROM PHYSICAL CAPACITY.
IT COMES FROM AN INDOMITABLE WILL.”*

—MAHATMA GANDHI

ASK THE DOCTOR

Dr. John M. Pellock, MD, addresses common questions and issues related to children and epilepsy.



Dr. Pellock is a professor and chair of the Division of Child Neurology at Virginia Commonwealth University in Richmond, Virginia. He specializes in the treatment of pediatric epilepsy and has been involved in the clinical development of new drugs to treat epilepsy in children and adults.

Q: Our child was diagnosed recently with epilepsy. How do we help other people caring for him understand how to handle him if he has a seizure?

A: All parents need to rely on others to help care for their children. Whether you have relatives, babysitters, or daycare teachers helping to look after your child, some education and planning can help make sure they're fully prepared to provide the special care your child needs.

All children are different, including those with epilepsy. What is your child like now? Caregivers should know how your child behaves on a day-to-day basis so they can recognize changes and signs of unusual behavior.



There are general questions caregivers should consider when your child acts differently from normal (see sidebar, "Caregiver Guidelines on Children With Epilepsy"). If there are signs of irritability, sluggishness, or a change in eating patterns, it might be due to side effects from medicine or a recent change in dosage. *(continued on page 4)*

Caregiver Guidelines on Children With Epilepsy

1. *Do you know how the child acts on a day-to-day basis? Are seizures completely stopped, or do some still occur? What do they look like? How many seizures are there on a typical day?*
2. *If the child becomes sluggish or irritable, or has a change in eating patterns, has there been a recent change in the dosage of his or her medicine? Could the behavior be a side effect to the medicine? Contact the parent to discuss what's happening.*
3. *If seizures occur and they are not expected to, are they "typical" of seizures the child had before being diagnosed? Contact the parent to describe the seizure in as much detail as you can and decide on an action plan.*
4. *If the child experiences a different kind of seizure, what does it look like? Is the child jerking and stiffening? Are there signs of shortness of breath? Turn the child onto either side (not back or stomach) and call 911 for emergency care, then contact the parent.*

In general, caregivers should try to describe any events that occur in as much detail as possible. This will help parents and doctors better evaluate the situation. Caregivers can write down relevant information about a seizure, but video taken on a cell phone or digital camera can be helpful for later evaluation, too.



(continued from page 3)

Caregivers should always know how to contact you to let you know when any behavioral changes occur, so you can provide this information to your child's doctor.

In addition, caregivers need to be able to recognize seizures and know what to do, should they occur. This means caregivers need to record detailed information about your child's seizures, so your child's doctor can evaluate them. If seizures occur, caregivers should contact you to discuss them. Together you can determine whether your child needs emergency help or not.

It is very important that caregivers recognize when another kind of seizure is happening. Is the child alternating between shaking or jerking and becoming stiff? Does the child become less responsive or even lose consciousness? Is breathing difficult? Because this might be an emergency, especially if the seizure lasts for several minutes, the caretaker should be instructed to call 911 for emergency help, and then call you.

Ultimately, caregivers for children with epilepsy need to be capable of handling the responsibility of taking care of a child with this condition. By providing them information and making response plans, both you and your caregivers can feel confident your child is getting the care he needs. Besides all of the things said, each family should have an emergency plan prepared for their child with epilepsy—it should include whom to call and why, along with the possibility of altering (usually adding) medications.

**THE MIRACLE, OR THE POWER,
THAT ELEVATES THE FEW IS TO
BE FOUND IN THEIR INDUSTRY,
APPLICATION, AND PERSEVERANCE
UNDER THE PROMPTINGS OF A
BRAVE, DETERMINED SPIRIT."**

—MARK TWAIN

VOICES

Phil Gattone relates his family's experiences after his son Philip's diagnosis.

Phil Gattone, president and CEO of the Epilepsy Foundation of Greater Chicago



Philip was 4 years old when he had his first seizure on April 11, 1991. It was shocking and scary for us as parents to find our son having a seizure. We weren't even sure if Philip was even alive when we found him because he was having difficulty breathing. Finding out that he had epilepsy was kind of a bittersweet answer because we knew what we were dealing with—but then we had to learn what path we could take next.



Philip Gattone as a boy, postsurgery

We were hoping that the more common treatment options would help control Philip's seizures. Unfortunately, every treatment we explored brought very limited success for a short amount of time. So we were frustrated at first, but then our frustration turned to anxiety, worry, and fear because over

months and then years, we saw that Philip's complex partial seizures were causing a serious decline in his ability to learn, concentrate, and remember.

Later, we learned that Philip's seizures were coming from one general area in his brain. Knowing this, we were able to pursue a new option, surgery, when Philip was 6 years old. This was partly successful, but the following year, he needed a second surgery. And though his seizures were less severe and frequent, they still occurred.

Finally, when Philip was about 7 or 8 years old, our doctor helped us find a drug that helped manage his seizures for a long time. He ended up graduating with honors in high school and completing his college degree in computer engineering. He is now working at a defense contractor with a team of engineers who design the computerized cockpit display in fighter jets.



Philip Gattone, today

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ONLINE RESOURCES FOR PEOPLE LIVING WITH EPILEPSY

A number of websites are designed to give support and information to those who are living with epilepsy. Here, we provide information on a broad range of websites representing a variety of perspectives. In each issue, we will take an in-depth look at one of the sites that you may find helpful.

The Epilepsy Foundation was established in 1967 and serves as a volunteer-based national resource for patients who have epilepsy and their families. The organization aims to help people with epilepsy fully participate in life's activities, and to help others become more accepting and understanding of those who live with epilepsy. The foundation also is involved in promoting clinical research for a cure. Notably, the foundation has established more than 50 local affiliate branches nationwide.

The foundation's website offers a wide range of information and materials for people of all ages, including educational videos and brochures. Patients and caregivers can choose to participate on bulletin board chat forums or establish their own blogs. News on key events—such as charity walks, congressional participation in epilepsy awareness, and government updates on the H1N1 virus—are included throughout the site. Patients can even subscribe to EpilepsyUSA, an electronic newsletter, or become involved in grassroots advocacy through this website.

Whether you're a 50-year-old patient who's been living with epilepsy for several years or the parent of a child with seizures, the resources and information available through the Epilepsy Foundation's website offer hours of reading. Visit the foundation's website at <http://www.epilepsyfoundation.org/> to see for yourself.



Other interesting websites for people living with epilepsy include the following:

Living With Epilepsy 101: The Basics—Down-to-earth advice on how to live well with epilepsy from epilepsy.com.

http://www.epilepsy.com/101/101_living

The University Hospital: Living With Epilepsy—

A page of this comprehensive website sponsored by the University of Medicine and Dentistry of New Jersey addresses lifestyle issues like driving, sports, sexuality, and aging.

<http://www.theuniversityhospital.com/epilepsy/html/aboutepilepsy/livingwith.htm>

Coping With Epilepsy—A free online forum for epilepsy discussions.

<http://www.coping-with-epilepsy.com/>

Epilepsy Meet-Up—A clearinghouse for finding live meetings and holding online discussions.

<http://www.epilepsy.meetup.com/>

Caring Parents—Help and research services to locate articles and other resources for parents and caregivers of children, including those with epilepsy.

http://caringparents.org/medical/epilepsy_10.php

Parents Helping Parents—Epilepsy Foundation's forum for discussion and support.

<http://www.epilepsyfoundation.org/living/children/parents/>

Families & Caregivers—Helpful information from epilepsy.com.

<http://www.epilepsy.com/info/family>



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