SUMMER SAFETY AND EPILEPSY

Summer is here, which means it’s time to enjoy all the fun that comes with warmer weather. Hiking, biking, swimming, horseback riding, barbecues, boating, gardening, house projects, and many more activities are part of what makes this time of year so wonderful.

As someone living with epilepsy, it’s important to participate in these fun activities for your physical, mental, and social health, but it’s also important to be mindful of safety.

First, always consult with your medical team before engaging in new activities to make sure they are appropriate for your individual situation. Second, make sure to let others know where and when you will be doing these activities. Even better, ask them to join you. Here are additional precautions to ensure your safety:

**Water**
- Use a buddy system
- Wear a life jacket
- Have a lifeguard or strong swimmer nearby
- Inform those around you of seizure first aid

**Fire**
- Sit far back from flames and fire pits
- Use fire guards or fire pits
- Use the buddy system

**Climbing**
- Use a safety harness and helmet
- Climb with a buddy

**Using Power Tools**
- Wear safety gear (goggles, helmets, guards, etc.)
- Use equipment with automatic stop switches
PARTICIPATE IN FITNESS AND FUNDRAISING

Athletes vs Epilepsy raises awareness and funds to support the Epilepsy Foundation’s work to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. Anyone can help with this effort that combines fundraising and physical activity. Here are some upcoming opportunities to participate.

Join the 2019 Summer Fitness Challenge! Athletes vs Epilepsy has partnered with the Wellness Institute for the Summer Fitness 26-day Challenge. We have taken all the guess work out of planning what to do and how to do it so that you can make an impact in the health and wellbeing of yourself and those around you living with epilepsy. Plus, it’s just 26 days! Each day you will receive a daily workout video designed by Wellness Institute Program Manager, Jenny LaBaw, to help you move towards a healthier you. For more information and to register visit AthletesVsEpilepsy.com/events/SFC

Recreation

- Use common sense when choosing your recreational activities
- Low-risk activities should be appropriate for most people living with epilepsy
- Medium-risk activities are dependent on the person and their type of epilepsy
- High-risk activities should be avoided until the person is seizure free for more than a year. Some health care providers recommend completely avoiding high-risk activities.

Click here to learn more about sports, exercise, and epilepsy.

*If your seizures aren’t under control, avoid swimming, pools, and open water; climbing to heights; and using power tools. If these can’t be avoided, make sure you have supervision.

EMOTIONAL HEALTH UPDATE

The Wellness Institute hosted a one-day Emotional Health Summit on March 23, in Atlanta, Georgia. The Summit brought together 40 people from across North America, including people with epilepsy, family members of people with epilepsy, and health care experts from different backgrounds. They discussed needs, barriers, and opportunities for addressing emotional health and epilepsy. It was a great day of sharing, learning, and connecting.

Emotional health refers to being aware of your feelings, moods, and behavior. It is important for all of us—people with epilepsy, family members, caregivers, and friends. It affects a person’s overall wellbeing and epilepsy management.

Emotional health also includes mood disorders such as:

- Depression
- Anxiety
- Thoughts of suicide

These mood disorders are more common in people with epilepsy. Research has shown that conditions such as depression can affect quality of life for a person with epilepsy more than seizures themselves. If you have concerns about your mood, thoughts, or behavior, seek help from your health care provider.

The Summit helped the Wellness Institute outline ways it can lead the Epilepsy Foundation’s efforts to improve emotional health for people with epilepsy and their loved ones. The Wellness Institute’s Live Well quarterly newsletter is available as part of the Epilepsy Foundation’s weekly news. Subscribe
ATHLETES VS EPILEPSY (CONTINUED)

Gear Up for Epilepsy (GUFE) was inspired by a young cyclist, Charlie, who dreamed of riding with his father across the United States. Unfortunately, he would not be able to accomplish that dream as his ride was cut short by SUDEP (sudden unexpected death in epilepsy) in August 2016.

On June 18, 2017, Charlie’s parents Clif and Arleen and numerous members of their family and community departed on a 2-month, 3,712 mile cross-country bicycle trek in honor of their son. They raised over $54,000 for the Epilepsy Foundation and the SUDEP Institute.

Join Athletes vs Epilepsy Gear Up for Epilepsy and help us honor those lost to SUDEP and support individuals living with epilepsy. Create your own cycling trek (using a bicycle or stationary bike) to help contribute to the miles ridden and funds raised for the Epilepsy Foundation. New this year—ride as a Road Warrior!

Interested in organizing your own group rides? Sign up as a GUFE Road Warrior. For more information on Gear Up for Epilepsy, visit AthletesVsEpilepsy.com/events/2019Gear.

For more information about Athletes vs Epilepsy, visit AthletesVsEpilepsy.com.

ON INDEPENDENT LIVING

For every person, life is constantly changing. We make day-to-day decisions based on factors we can control and some we cannot. Autonomy is the ability to have choices over your life and the resources and supports that you use.

Living with epilepsy can sometimes pose challenges that limit autonomy. Taking time to consider where you are in your epilepsy journey and what factors might influence your independence will allow you to set personal goals for autonomy. Reflecting on your situation and planning ahead will help you make decisions that keep you healthy, happy, and safe.

Veronica Crowe was diagnosed with epilepsy when she was 14. As she and her family learned more about epilepsy, they realized that she had been having seizures for years but had been unaware of what they were. The number of seizures increased throughout high school and college. “At times I thought I would have to quit college because of the increase of seizures and stress,” says Veronica.

Veronica made the decision to join a clinical trial to avoid having brain surgery. “After the clinical trial, I started speaking about my struggles with epilepsy and how I’ve overcome them. It made me much more comfortable talking about having epilepsy in public. Before that, few knew,” says Veronica.

Later Veronica served on the board of directors of the Epilepsy Foundation Texas—Houston/Dallas-Forth Worth/West Texas. She enjoyed the work so much that she decided to leave a comfortable and safe 13-year job as a law librarian where she had no opportunities to grow and, instead, pursue a career in the nonprofit sector despite having to move away from home. “I lived with my mom the majority of my life,” says Veronica.
WE'D LOVE TO HEAR FROM YOU

- Do you have a question about diet, nutrition, physical activity, sleep, or other dimensions of wellness?
- Want to share your healthy habits?
- Do you have a great trick for managing your stress?

We'd love to share your questions, ideas, or success stories in an upcoming issue of our newsletter. Email us at wellness@efa.org. Photos would be great, too.

Veronica earned a master's degree in public administration and is now the Manager of Foundation Relations at the Epilepsy Foundation. She follows these steps so she can live independently, “I take my medications correctly each day, try not to let any issues overstress me, and get plenty of sleep.” She is under the care of an experienced epileptologist to help keep her healthy.

Below are suggestions from Dr. Elaine Kiriakopoulos, a neurologist and Director of Health Communications & Engagement at the Epilepsy Foundation, to help people with epilepsy build autonomy:

**Acceptance:** accept where you are today, be proud of the things you can do and identify aspects of your life you’d like to improve

**Support:** establish a peer and community support network

**Positivity:** believe you can self-determine your health care and your life goals

**First Steps:** build momentum by taking control of small daily decisions and tasks before tackling more difficult decisions

**Routine:** establish a routine that provides control and consistency

**Social relations:** engage in community activities, volunteer, organize dates with friends

**Overall health:** eat well, get adequate rest, and exercise regularly to improve physical and mental wellness, which leads to greater confidence and ability

Dr. Kiriakopoulos says, “Caregivers can play a critical role in helping loved ones develop autonomy. Open, honest communication is key in helping to determine the possibilities for independent living. A willingness to support and build independence will offer a sense of control and relieve stress for everyone.”

She continues, “Remember, independent living is a dynamic process that will change with time just as every person’s abilities and needs change over a lifetime. If you are a caregiver, you can help your loved one to reflect on where they are in their epilepsy journey, help them to set reasonable goals, and assist them in finding supports to strengthen their chances of achieving the level of independence they desire.”

Dr. Kiriakopoulos has additional advice for people with epilepsy, “Chronic illness, including epilepsy, can sometimes make it more difficult to work. Living independently can often present financial challenges. A social worker, community health worker, or case manager can help you explore options for maintaining your independence. Your medical team can refer you to a provider who can help you set realistic and attainable goals as well as direct you to local, state, and federal resources. Your local Epilepsy Foundation office can also help to guide you to community resources.

For more information on Independent Living, visit epilepsy.com/living-epilepsy/independent-living.