



WELLNESS AND EPILEPSY



EPILEPSY
FOUNDATION

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INSTITUTE

About the Epilepsy Foundation: The Epilepsy Foundation, and its network of 50 organizations throughout the United States, leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives. To learn more, please visit epilepsy.com.

Disclaimer: This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting with their health care provider.

WELLNESS & EPILEPSY

What is wellness?

Wellness refers to a healthy balance of mind, body, and feelings. Wellness is also an approach that focuses on a person's health and how to prevent and manage medical problems. The emphasis is on health and well-being, rather than a specific disease. The term wellness may be used to describe a person's overall health, happiness, and comfort. Reaching a state of wellness is:

- ▶ Ideally self-directed and community supported
- ▶ A conscious and active process
- ▶ Making choices that lead toward a healthy and fulfilling life



Why is wellness important for people with epilepsy, their families, and caregivers?

We all need to take care of ourselves—to manage individual health problems and get or stay healthy and happy, despite health problems. A health condition like epilepsy is important to wellness, but is not the only factor. It's important to consider the way epilepsy and treatment affects your health, well-being, and daily life.

What is self-management?

Self-management is the term used to describe the steps people take to manage their health and wellness. For people with epilepsy, there are two key areas:

Epilepsy-Specific Self-Management: This area includes what people do to manage seizures, medicines, other treatments, safety, or anything specific to managing epilepsy. Examples of these include managing:

- ▶ Seizures (knowing seizure types, seizure first aid, recognizing triggers, keeping a seizure diary)
- ▶ Treatments (taking medications properly; affording medicines; and making decisions about diagnostic tests, surgery, or devices)
- ▶ Safety (assessing risks, using seizure precautions, preventing seizure emergencies, making seizure response and safety plans, talking about sudden unexpected death from epilepsy [SUDEP] and ways to lessen risks)
- ▶ Comorbid conditions (recognizing and managing other health problems that may happen with epilepsy, such as sleep problems, injuries, problems with mood, thinking, or behavior)

Managing Life with Epilepsy: The second major part of self-management is what medical professionals call “chronic care management.” In essence, this includes steps for healthy living and managing life with epilepsy. Some of these issues may be similar to what people do for other chronic health problems. This area may include:

- ▶ Keeping a healthy lifestyle

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- ▶ Identifying and treating other health problems early
- ▶ Having an active partnership with your health care team
- ▶ Coping with how epilepsy affects your daily life and independence

The Managing Epilepsy Well Network (managingepilepsywell.org) provides a number of self-management programs, such as UPLIFT, PACES, and HOBSCOTCH, to help people with epilepsy.

If you live with epilepsy, seizure control can be enhanced by looking after your overall health and your epilepsy. And for people who care for someone with epilepsy, taking care of your own health is very important. Sick, stressed, or sleep-deprived families or caregivers are unable to provide quality care.

Paying attention to your health and wellness is critical to how all our brains function. Focusing on your overall wellness using a holistic approach looks at your whole body and how you interact with your environment. This approach to health can have benefits:

- ▶ Lower health care costs
- ▶ Healthier body & brain
- ▶ Less stress
- ▶ Improved emotional health
- ▶ Better frame of mind to tackle day-to-day activities

What are the dimensions of wellness?

Wellness includes many different areas of your life that may be affected by epilepsy or other health concerns. The Wellness Wheel highlights key areas to look at.

How each area is affected may vary depending on your age, support, health, and other unique issues. Pay attention to each dimension and how it may relate to the other dimensions. Improving one dimension can also improve the others. And, neglecting one dimension can make the others suffer.

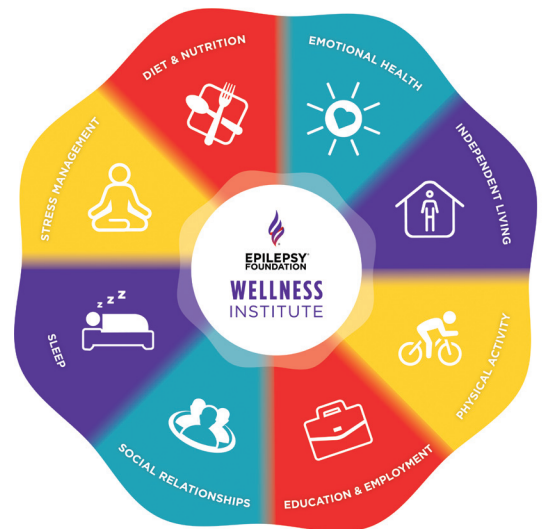
How can I start to improve my wellness?

Understand yourself—mind, body, emotional health, finances, and social situation. Finding out what bothers you most or is most important may be a good place to start. Assess your health and your lifestyle. Review this with your health care team. Then pick one or two areas to focus on. Don't try to change everything at once—start small and then build on your successes.

Ways to begin and make changes for the better.

Self-Belief

This is the most important part of changing your behavior(s) and motivating yourself. Truly believe in your change. Believe in WHY you're trying to change. And believe you can do it. Having a positive mindset will make it easier to follow through when you're faced with temptation or stress.



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Self-Discipline and Patience

It takes hard work, consistency, and dedication to make lasting change. People looking for a quick fix are setting themselves up for disappointment. It takes consistent practice and time to build self-discipline. Just like building muscles, you need to work at it. Be patient and trust the process.

Be Honest with Yourself

Give yourself some tough love. Be honest with yourself and aware of the choices you're making. If you have trouble making changes, ask why. Are you sabotaging yourself or did you just have a minor slip up? Either way, identify the problem and take that next step forward.

Focus on the Positive

Turn off the negative voices. Being optimistic makes it easier to move forward and stick with changes when life gets stressful.

Set S.M.A.R.T. Goals

To ensure clear, reachable goals, follow the SMART guidelines.

Specific: Simply written and clearly defined

Measurable: Be able to measure when you have met the goal

Achievable: Goals to stretch you, but realistic to achieve

Relevant: Reasonable, realistic, and results-based

Time-bound: Set a time frame with a practical sense of urgency

Start Small at First

We are motivated by success. Once you've set your priorities and goals, make smaller, actionable plans to achieve those goals. Check in with yourself regularly (daily, weekly, monthly) to make sure you are still on track. Tracking your progress helps you see moments of success as you make changes.

Share with Your Friends

Share your goals with those you care about—support can help you stick with it. Share your progress—ask them to check in with you, or maybe join you in this new habit.

Celebrate!

Make sure to celebrate your successes throughout your journey. Make your celebration complement your goals. For example, after eating healthy for one week, treat yourself to a movie with friends rather than a bowl of ice cream.



FOR MORE INFORMATION

- ▶ Epilepsy Foundation Wellness Institute: epilepsy.com/wellness
- ▶ My Seizure Diary: diary.epilepsy.com
- ▶ Epilepsy & Seizures 24/7 Helpline: 1-800-332-1000, en Español 1-866-748-8008, epilepsy.com/helpline
- ▶ Find Your Local Epilepsy Foundation: epilepsy.com/local

EDUCATION & EMPLOYMENT

Epilepsy, especially when seizures are well-controlled, has little or no impact on school performance for many students. However, seizures and the underlying cause of seizures can result in problems with learning, memory, attention, and other skills needed to succeed in school.



Most people with epilepsy are able to work and be productive in many fields. Sometimes seizures can interfere with a person's ability to work. Having frequent or even occasional seizures may make it hard to find or keep a job, but it's not impossible.

EDUCATION

- ▶ About 1 in 2 students with epilepsy have some form of learning difficulties and may need extra help.
- ▶ Learning problems may be hard to detect.
- ▶ Students may have difficulties with language, memory, attention, and problem solving.
- ▶ Some seizure medicines may cause side effects that affect learning and memory.
- ▶ Some types of epilepsy may have medical or neurological problems that can affect learning and school performance.



The impact of seizures on learning may depend on many factors such as:

- ▶ The age seizures start
- ▶ Cause of seizures
- ▶ Age when treatment begins
- ▶ How often seizures occur
- ▶ Where seizures arise in the brain
- ▶ How well a student responds to treatment

Identifying learning problems early is key to getting the right help and maximizing a student's learning.

EDUCATION & EMPLOYMENT

Is help available for students with epilepsy?

Everyone has the right to a free public education in the United States. Section 504 of the Rehabilitation Act outlines that all people, including those with disabilities, have a right to participate in programs and activities that receive federal funding from the US Department of Education. This civil rights law ensures that students with epilepsy cannot be discriminated against in public school settings.

- ▶ All students with seizures who may be having learning problems are eligible for an assessment of their learning and educational needs.
- ▶ Some students with epilepsy may need individualized support in a school environment, such as an individualized education plan (IEP) or 504 plan.
- ▶ Telling the school about a student's epilepsy is the first step to getting the help they need. Talk with your epilepsy doctor about school and how you or your child are doing.
- ▶ Neuropsychology testing may be recommended to assess the student's strengths and difficulties.



How will having epilepsy affect my child in school activities?

School activities are a way for kids to develop social skills and try new things. It's important to assess each child's needs, restrictions, and safety concerns for school activities. Make sure that all school personnel are taught seizure first aid and that people in charge are aware of any IEP, 504 plan, or seizure response plan. For safety tips to prevent injury, visit epilepsy.com/safety.

How can I advocate for my child in school?

Know the school policy: The school is required to provide for student needs so they can have a positive school experience.

- ▶ Staff members should know how to help students with epilepsy.
- ▶ Risks of school activities inside and outside of the normal school day (holiday activities, field trips, etc.) should be assessed and planned for.

Have an IEP or 504 plan: Inform the school about the student's epilepsy. The school must make sure that needs are met and staff are trained to give support.

- ▶ An IEP defines the support the student needs, when they need it, and who is responsible for making sure these needs are met.
- ▶ A 504 plan includes accommodations that a student may need but does not include specialized educational needs. Accommodations may include extra time to take tests or complete homework, a quiet area to recover, tutoring, or modified class times.

EDUCATION & EMPLOYMENT

- ▶ Not all people with epilepsy will need an IEP or 504 plan. Talk to the student's guidance counselor, teacher, and school nurse about their needs.

Develop a Seizure Response Plan:

Creating a seizure action plan is important for every student with epilepsy (bit.ly/seizureresponse). It should be clear, yet concise, and include information about the student's typical seizures, medicines, when additional help is needed, first aid steps, and if rescue therapies may be needed.

- ▶ Work with the school nurse and your epilepsy health care team to develop the seizure response plan.
- ▶ Seizure response plans should be included in IEPs and 504 plans too.



EMPLOYMENT

Living with some forms of epilepsy can create challenges that affect the ability to work.

- ▶ **Safety**—seizures with falls or high risk of injury may be unsafe in certain work environments
- ▶ **Ability to drive**—not being able to drive due to uncontrolled seizures may make it hard to get to work or perform jobs that require driving
- ▶ **Developmental disabilities**—some forms of epilepsy are associated with developmental problems that may prevent people from being gainfully employed
- ▶ **Mild to moderate cognitive problems**—problems with memory, thinking, or attention may make certain types of work difficult
- ▶ **Side effects**—sleepiness, memory problems, or lack of coordination/balance may interfere with some types of work
- ▶ **Healthcare visits**—frequent visits, tests, hospitalizations, or the time needed for recovery after seizures may affect work schedules
- ▶ **Other neurological or medical problems** may affect the ability to work



What type of work can I do?

Just like anyone else, the better qualified you are for a position, the better your chances of success. If your seizures are under control, almost all jobs should be open to you. Some jobs (such as police, firemen, military, or airline pilots) have special regulations that may exclude people with epilepsy who are still having seizures or taking seizure medications.

EDUCATION & EMPLOYMENT

If you don't yet have full control of your seizures, consider jobs that:

- ▶ Don't require driving
- ▶ Don't have dangerous work environments
- ▶ Allow work from home
- ▶ Allow flexible hours

Is epilepsy covered by the ADA?

The Americans with Disabilities Act (ADA) prohibits discrimination in the workplace on the basis of a person's disability. The ADA grants all individuals with disabilities uniform protections regardless of which state they live in. The 2008 Americans with Disabilities Act Amendments Act (ADAAA) makes it clear that people with conditions such as epilepsy are covered by the ADA and protected from discrimination on the basis of their epilepsy.

Should I disclose my epilepsy to my employer and co-workers?

You do not need to tell an employer about your epilepsy or other disability unless you want to or if you may need accommodations to do your job. Examples of reasonable accommodations for a person with epilepsy may include:

- ▶ Changes in the workspace to prevent injury if a seizure should occur
- ▶ Training workers on seizure first aid
- ▶ Change in work hours to allow for reasonable breaks or to minimize seizure triggers
- ▶ Use of written or technology aides to help with memory or learning problems
- ▶ Time off or flexible work hours for tests, hospitalizations, or medical visits



Some people tell employers and coworkers about their seizures so those around them know what to do if they have a seizure.

What type of help is available for work-related problems?

Anyone with epilepsy who is having trouble at work or difficulty finding or keeping a job should ask to see a vocational rehabilitation specialist. Vocational counselors can help assess a person's job readiness and skills, teach new job skills, help find a job, or provide coaching to help workers succeed in their job. Your local Epilepsy Foundation office may offer job help too.

How can I learn more about my rights in the workplace?

The Epilepsy Foundation can help you learn about your rights and responsibilities, as well as how to ask for reasonable accommodations. If you are concerned about discrimination at work or have other legal concerns, please contact the Epilepsy Foundation's Jeanne A. Carpenter Legal Defense Fund (epilepsylegal.org).

FOR MORE INFORMATION:

- ▶ Employment and Epilepsy: epilepsy.com/employment-and-epilepsy
- ▶ Seizure Response Plan: epilepsy.com/responseplans
- ▶ Advocating for Your Rights: advocacy.epilepsy.com
- ▶ U.S. Department of Labor CareerOneStop: careeronestop.org
- ▶ Job Accommodation Network: askjan.org
- ▶ Legal Rights for People with Epilepsy: epilepsylegal.org

PHYSICAL ACTIVITY

Note: Always consult with your medical team before engaging in new physical activity.

What is physical activity?

Physical activity simply means movement of the body that uses energy. Any time you are moving your body, you are getting physical activity. Any type of movement is healthy, but being active for an extended period of time seems to have the most health benefits. Some examples are:

- ▶ Walking, running
- ▶ Gardening, housecleaning
- ▶ Lifting weights
- ▶ Yoga
- ▶ Martial arts
- ▶ Dancing
- ▶ Riding a bike, roller blading, skate boarding
- ▶ Playing a sport



Why is physical activity important for people living with epilepsy, their families, and their caregivers?

People with epilepsy get the same health benefits from exercise as people without epilepsy. Regular exercise provides physical and emotional benefits such as:

- ▶ Increased stamina, strength, flexibility, and balance
- ▶ Weight and fat loss
- ▶ Improved mood
- ▶ Reduced stress
- ▶ Improved quality of sleep
- ▶ Lower risk of illness
- ▶ Increased bone density and reduced risk of osteoporosis



PHYSICAL ACTIVITY

For individuals with epilepsy and seizures, exercise may help:

- ▶ Seizure control
- ▶ Reducing some side effects of seizure medications
- ▶ Mood problems or stress
- ▶ Sleep (lessen the risk of sleep deprivation triggering seizures)
- ▶ Cognition (thinking, memory, attention)
- ▶ Overall quality of life

How much and how often should I exercise each week?

The US Department of Health and Human Services gives the following physical activity guidelines for adults.

Aerobic Activity:

- ▶ 150 minutes of moderate aerobic activity or 75 minutes of vigorous aerobic activity weekly
- ▶ Ideally time is spread out over the course of the week

Strength Training:

- ▶ At least 2 days a week
- ▶ Ideally exercising all major muscle groups of the body



The physical activity guidelines vary for different age groups. Please consult with your medical team for your individual recommendations.

How can I get more active and exercise if I have other medical problems or disabilities too?

People with seizures may have other medical problems that affect their ability to move around, do daily activities, or join exercise programs. Don't let these problems get in your way.

To get started, talk to your health care team about what is getting in the way of being physically active. It's important to know the cause so you can find ways to address it.

- ▶ If pain limits activity and exercise, you need to find the source of pain and get help for this first. Exercise may be part of the solution, but talk to your health care team first.

PHYSICAL ACTIVITY

- ▶ If muscle weakness or coordination problems are part of the problem, exercise may help. Also, activities can be adapted to your strength and coordination.
- ▶ If you have trouble walking or tend to fall, do exercises lying down or in a chair.

How do I know what types of activity are right for me?

Talk to your health care team about your health and recommended activity. If you have not been exercising or have other medical problems or disabilities, ask to see a physical therapist (PT). They can:

- ▶ Treat some health problems with specific exercise plans
- ▶ Help design an exercise program tailored to your needs
- ▶ Work with you individually on specific problem areas
- ▶ Show you how to do exercises on your own
- ▶ Do a home safety evaluation

How can I stay safe while being physically active?

Safety is always the top priority. Talk to your health care team about your safety risks. Then make a safety plan that includes what you can do, how to increase activity, what activities to avoid, and what precautions you may need.

Most activities are safe for people with epilepsy even if their seizures aren't fully controlled. However, the more severe a person's seizures, the greater the need for that person to limit or modify activities. Some examples of safety tips:

- ▶ Keep your medical alert information with you at all times, including what to do if you have a seizure.
- ▶ Use common sense—certain activities may need special accommodations or should be avoided (rock climbing without safety equipment, scuba diving, skydiving, etc.)
- ▶ Exercise with a buddy.
- ▶ Always have close supervision when swimming or doing water sports. For some people, it may be safest to avoid activities around water.



PHYSICAL ACTIVITY

- ▶ Avoid exercising at the hottest times of the day.
- ▶ Exercise in safe places—walk, run, or bike in parks or on bike paths, not on busy streets.
- ▶ Work out on soft surfaces if you are at risk for falls.
- ▶ Use safety equipment appropriate for the activity and your seizure type.
- ▶ Always wear a high-quality, properly fitted life vest when near the water.
- ▶ Wear a helmet to protect your brain during activities at risk for falls.

How do I get started?

Start where you are today. That may mean walking around the block or up and down your stairs. It may mean joining an exercise class. Find an activity that you will enjoy so you're more likely to stick with it. The main thing is to start moving today and keep at it.

Below are some ways to help stick to a fitness routine.

- ▶ Schedule it in your calendar.
- ▶ Find a workout partner.
- ▶ Schedule an appointment with a trainer/fitness professional.
- ▶ Track progress.
- ▶ Keep in mind why you want to be more physically active.
- ▶ Wear a helmet to protect your brain during activities at risk for falls.

FOR MORE INFORMATION:

- ▶ Fitness and Exercise: epilepsy.com/wellness-fitness-exercise
- ▶ CDC Physical Activity: cdc.gov/physicalactivity

INDEPENDENT LIVING

What is independent living?

Independent living refers to being able to make informed decisions and to direct your own life. It does not necessarily mean that you live on your own or don't need help. It does refer to having choices about the type of resources and supports you need to live as independently as possible. The choices that you or your loved ones make may change over time.



Why is independent living important for people with epilepsy and their caregivers?

Managing epilepsy (epilepsy.com/learn/managing-your-epilepsy) is more than just knowing how to handle the medical aspects of seizures or knowing how to stay safe. People also need to think about how epilepsy can affect day-to-day needs and plans for the future including their ability to:

- ▶ Get an education
- ▶ Get and keep a job
- ▶ Have accessible transportation
- ▶ Take care of household chores
- ▶ Be involved in their medical plan
- ▶ Have resources or support for housing or supported living
- ▶ Access peer support or community resources
- ▶ Know their own rights and freedoms



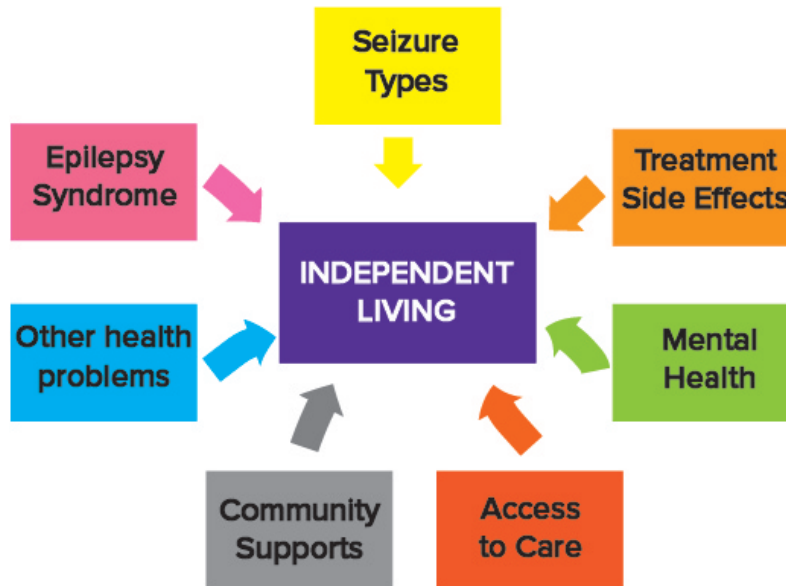
Some facts about independent living and epilepsy:

- ▶ 1 in 5 adults with active epilepsy live alone.
- ▶ 1 in 3 adults with epilepsy are not able to work.
- ▶ About 1 in 10 adults are limited at work due to their epilepsy.
- ▶ 1 in 3 parents of children with epilepsy worry that food will run out before they get more money.

INDEPENDENT LIVING

Many factors can affect a person's ability to live independently.

CONSIDERATIONS FOR INDEPENDENT LIVING



How is a person's ability to live independently determined?

Determining your abilities, limitations, and needs will help you set realistic goals for independent living. Some factors to consider when you are setting goals and making decisions include:



Cognitive function: thinking, memory, problem solving, or making decisions

Language/communication: talking, understanding, expressing needs

Sensory limitations: vision or hearing problems

Activities of daily living: caring for oneself (called self-care) such as bathing, dressing, and eating

Mobility: walking or moving around

Employment: working or having regular daily activity, for example paid work, volunteer work, or day programs

Transportation: driving or having access to public or other transportation

INDEPENDENT LIVING

What types of help for housing are available if I can't live on my own?

A variety of living options are available, but resources will vary depending on needs, where you live, financial status, eligibility for disability supports, health insurance, or other types of financial assistance. Some examples of help:

Help in the home: People living alone or with friends/family may be eligible for help from a visiting nurse, personal care attendant, or volunteer agency for some needs. This type of help is usually intermittent for a few hours at a time or a few days a week. It is not designed to provide constant help or supervision.

- ▶ Home health agencies and long-term care pharmacies can offer help to make taking medications easier. Medications can be sent by mail or prepacked to prevent forgetting or mixing up doses.
- ▶ Home evaluations can be done to check on safety risks and ways to prevent injury. This is especially helpful for people with uncontrolled seizures and tendency to falls.

Supported living: This refers to the help a person may need to live in a private home or a group home setting. The type of help may vary over time and is usually coordinated by a community agency that specializes in independent living support.



Residential care: Some people need more help or someone to provide supervision or direct care 24 hours a day. These settings provide help with basic personal care, medication management, and transportation. Some may provide opportunities to participate in day programs, work programs, or social activities as well.

- ▶ **Groups homes:** Usually have a small number of people with disabilities in a residence, staffed by direct care providers. Nursing help may or may not be available in the home.
- ▶ **Assisted living facilities:** These facilities are geared to seniors, but some may also provide living support to younger people with disabilities.
- ▶ **Nursing homes:** People in a nursing home need care and monitoring for complex health needs 24 hours a day. Skilled nursing care as well as rehabilitation therapy is available.

How do I improve my ability to live independently?

Whether you are the person living with epilepsy or the caregiver, developing independence can help build a sense of control and relieve stress for everyone. Below are some tips to help you begin thinking about independent living.

- ▶ **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 make the necessary changes to live independently.
- ▶ **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.

FOR MORE INFORMATION:

- ▶ Find Your Local Epilepsy Foundation: epilepsy.com/local
- ▶ Epilepsy & Seizures 24/7 Helpline: 1-800-332-1000, en Español 1-866-748-8008, epilepsy.com/helpline
- ▶ Administration for Community Living: acl.gov

Emotional health involves being aware of your feelings, mood, and behavior. The terms mental health and behavioral health are often used too. Positive emotional health means being able to accept feelings and to find ways to enjoy life despite challenges. Emotional health, just like physical health and the other dimensions of wellness, is an important part of overall well-being.



Emotional health is important for all of us—people with epilepsy, family members, caregivers, and friends. Stress, depression, and anxiety can have a direct impact on our emotional health. These problems can also affect how we feel physically.

What are common reactions that people with epilepsy may feel?

Epilepsy can affect your emotional health in many ways and at different times. Changes may happen with the first seizure, when someone is told they have epilepsy, and later if seizures are not controlled.

- ▶ Seizures can result in a loss of predictability in a person's life. If, or when, seizures may occur cannot be predicted.
- ▶ The loss of predictability may make people living with epilepsy and their caregivers feel insecure. If these feelings are not addressed, symptoms of depression and anxiety may develop. Family or friends may become overprotective and family conflicts may occur.



- ▶ People living with epilepsy may not recognize their reactions at first. It's important to talk openly with the healthcare provider about the diagnosis and how you feel at the first visit or as early as possible.
- ▶ People may also worry that others will treat them differently because of their epilepsy. This can affect one's self-confidence and how they feel about themselves.

People may feel scared, worried, or angry later, especially if seizures are not controlled or other challenges happen. In short, coping with the emotional impact of epilepsy can feel like a roller coaster, with many ups and downs.

Below are some examples of how epilepsy may impact your emotional health.

- ▶ Fear, sadness, or shock after being diagnosed with epilepsy
- ▶ Worry about when or where the next seizure may happen
- ▶ Anger if epilepsy prevents you from driving or doing activities independently
- ▶ Being afraid or embarrassed to tell others about your epilepsy
- ▶ Feeling stressed

Sometimes the feelings can be overwhelming and affect all aspects of a person's life. Symptoms of depression and anxiety may develop. It's important to tell your healthcare provider if these feelings last or if you are unable to enjoy your usual activities.

Does epilepsy and seizure medicines affect emotional health and behavior?

Certain areas of the brain that are commonly affected by epilepsy play an important role in our emotions. People with seizures in these areas may have an increased risk of depression or anxiety compared to the general population. Here are some other examples:

- ▶ Fear could be part of a seizure if it happens suddenly and the same way each time.
- ▶ Some people may notice changes between seizures or after a seizure, such as mood swings, irritability, or feeling more emotionally sensitive.
- ▶ Some seizure medicines may make a person more irritable, down, or depressed. This happens more often in people who have a mood disorder or had problems in the past. A family history of mood problems may also increase the risk of medicines affecting mood.
- ▶ Some medicines used to treat seizures may also help mood and anxiety disorders.
- ▶ Occasionally, some seizure medicines can cause suicidal thoughts. This is more likely to happen in people with a personal or family history of mental health problems.



Can having epilepsy make a person more likely to have depression or anxiety?

Anxiety and depression happen more often in people with epilepsy than in people without epilepsy. About 1 in 3 people with epilepsy may have difficulties with anxiety or depression at some point in their life. These problems happen more often in people with uncontrolled epilepsy. Yet the relation between depression, anxiety, and epilepsy is complex. People with anxiety or depression also have an increased risk of developing epilepsy. We still don't know why this

happens, but we know that epilepsy and these mental health problems affect the brain in similar ways.

It's important to recognize and treat changes in mood and anxiety quickly, as they can affect quality of life (and that of the family) more than the seizures alone. Also, failure to treat mood problems can worsen seizure control.

- ▶ People may be more prone to side effects of medicines.
- ▶ People may have more trouble remembering or taking medicines regularly.
- ▶ Certain seizure medications may make mood worse.
- ▶ People may have more trouble coping with stress, which can worsen seizures in some people.

Talk to your healthcare team as soon as any problems begin and if changes arise.

Why is emotional health important for caregivers?

Loved ones and caregivers should pay attention to their own emotional health too. Caring for others and living with epilepsy can be stressful. Often family and friends need to take time away from work, school, or other family commitments. Meeting competing needs causes added stress and challenges. Unhealthy caregivers cannot give their best care to their loved ones.

- ▶ Talk to your own primary care provider about your feelings and stressors
- ▶ Seek a support group or mental health professional for help

What can I do to manage or improve my emotional health?

The first step is being aware of your emotional health and seeking help from a healthcare professional when you have questions or concerns. Some people believe that there is a stigma associated with seeking help for your mood or stress. However, just as you should get a physical check-up for your body, you should also get an emotional check-up by talking to your provider about any emotional health concerns. There are several activities and behaviors you can build into your routine too:

- ▶ **Build a social network.** Positive social and family relationships may help you find support during difficult times. Also, engaging in enjoyable activities with others may help lift your mood.
- ▶ **Exercise regularly.** It doesn't matter what form of physical activity you choose—just move.
- ▶ **Eat a healthy diet.** Nourishing your body with healthy food choices has added benefits for your mental health and well-being.
- ▶ **Reduce your stress.** Many stress management techniques, such as mindfulness, meditation, creating art, or journaling, can lessen your feelings of depression.
- ▶ **Practice new thinking strategies.** Are there other ways you can look at your problems and find a silver lining? Problems are real, as are the feelings we associate with them. But how we think about our problems can make them worse, or better than they first appear. The Managing Epilepsy Well (MEW) Network (epilepsy.com/learn/managing-your-epilepsy/self-management-programs) has programs that can help.

EMOTIONAL HEALTH

- ▶ **Volunteer and help others.** Consider helping someone who is less fortunate or volunteering for an organization that is of interest to you. Devoting time to help others will give you the chance to interact with them and may give you a feeling of accomplishment. Find out how to get involved with the Epilepsy Foundation (epilepsy.com/make-difference/get-involved) nationally or in your community (epilepsy.com/affiliates).
- ▶ **Practice gratitude.** It isn't easy to be objective when life and its problems are overwhelming. But, if you pause and reflect, there are people and things that you can be grateful for in your life. These can give you a sense of perspective as well as hope for the future.
- ▶ **Ask for help.** We would all love to be self-sufficient, but sometimes trying to deal with your problems on your own can be too difficult. Everyone needs a helping hand.



FOR MORE INFORMATION:

- ▶ Emotional Health: epilepsy.com/emotional-health
- ▶ Mood and Behavior: epilepsy.com/moods-behavior
- ▶ Epilepsy & Seizures 24/7 Helpline: 1-800-332-1000, en Español 1-866-748-8008, epilepsy.com/helpline
- ▶ National Suicide Prevention Hotline: 1-800-273-8255

CAREGIVERS & EPILEPSY

Caring for someone with a chronic condition such as epilepsy can be overwhelming and stressful. There may be day-to-day demands, such as making sure medications are taken on time, giving first aid during seizures, and going to appointments with health care providers. Some people need “hands on” help or support from family or caregivers 24/7. Caregivers may need to make sure their loved ones have access to education and other support for legal and financial issues. When family members/caregivers are the main decision makers and managers, tasks can seem endless. It is critical that caregivers take proper care of themselves, too. Here are a few tips to help caregivers stay well and be at their best.



Recognize symptoms of overload and burnout

It's important to recognize the symptoms of caregiver overload or burnout before they become too severe and cause physical problems.

- ▶ Isolation from friends, family, and other loved ones
- ▶ Loss of interest in activities that were previously enjoyed
- ▶ Feelings of sadness, irritability, and hopelessness
- ▶ Changes in sleep habits, appetite, and weight
- ▶ More likely to get sick
- ▶ Intense physical and emotional fatigue (exhaustion)
- ▶ Chronic stress or anxiety



Understand the causes

- ▶ **Demands:** Caring for others can be physically, mentally, and emotionally demanding.
- ▶ **Overlap of roles:** The role as caregiver adds to a current roles as parent, spouse, partner, offspring, sibling, or friend. The caregiver may need to help with different activities several times each day, such as physical, occupational, or speech therapies.
- ▶ **Unmet expectations:** Some caregivers expect their performance to improve the health and happiness of the patient when this is not always possible.
- ▶ **Loss of control:** Seizures and other problems are often unpredictable, leading to a feeling of loss of control.
- ▶ **Unreasonable demands:** When someone is not well, they may have unreasonable demands out of their own frustration and anger with having epilepsy.

CAREGIVERS & EPILEPSY

Managing caregiver overload

Steps to help prevent and treat caregiver burnout and physical or emotional exhaustion:

- ▶ **Talk to friends.** Find someone you trust, such as a friend, a coworker, or a neighbor to talk about your feelings and frustrations. Parents of a child with epilepsy may find it helps to talk to other parents in similar situations.
- ▶ **Have realistic goals.** Accept when you need help in caring for your loved one and take action by asking for and accepting offers of help from others. Be realistic about your loved one's health, but maintain hope. Stay in touch with the epilepsy care team and make sure you have the latest facts and treatment options.
- ▶ **Nurture yourself.** Plan free time for yourself, even if it is a few hours on a regular basis.
- ▶ **Seek professional help.** Most therapists, social workers, and members of the clergy or church are trained to counsel people who face physical and emotional difficulties or challenges.
- ▶ **Use respite care services.** Respite care provides short-term relief for primary caregivers. These can give you a brief or longer break from your activities.
- ▶ **Know your limits.** Take a real check of your personal situation. Recognize and accept if you are overloaded or emotionally stressed.
- ▶ **Manage your expectations.** Don't try to do everything. Simplify your meals, extracurricular activities, and holidays.
- ▶ **Learn about the illness of your loved one.** The more you know about the illness, the more effective you will be caring for or helping your loved one.
- ▶ **Develop skills to overcome challenges.** Remember to emphasize positive things. Use relaxation techniques, such as mindfulness, yoga, or deep breathing to help you cope with day-to-day challenges.
- ▶ **Laugh.** Your sense of humor can help you deal with the stress of each day.
- ▶ **Practice healthy habits.** Maintain your well-being by eating healthy foods, exercising, and getting enough sleep.
- ▶ **Accept your feelings.** Having negative feelings—frustration or anger—about your responsibilities or the person you are caring for is normal and human.
- ▶ **Foster and prioritize your primary relationships.** Do something fun with a loved one 5-10 minutes a day or 1 day a month.
- ▶ **Join a support group.** Sharing your feelings with others in the same situation can help you manage stress, find sources of help, and decrease feelings of frustration or isolation.
- ▶ **Consult your doctor.** If you already suffer from stress and depression, seek medical help.



CAREGIVERS & EPILEPSY

Explore other sources of help if you're feeling overloaded

Overload and burnout can be prevented. Consider the following resources:

- ▶ Home help and respite services are agencies that provide in-home help and nurses for short-term care.
- ▶ Day care for adults are programs that offer a place for your loved one to socialize, perform various activities, and receive medical help and other services.
- ▶ Nursing homes or other institutions provide residential places on a temporary basis to provide caregivers with a respite from their responsibilities.
- ▶ Private services may be available from professionals to help coordinate care needs.
- ▶ Other support services for the caregiver include support groups and other programs that can help caregivers “recharge batteries” and meet other people who are facing similar situations, find more information, and locate additional sources.



Remember that the Epilepsy Foundation can help you find the information and help you need.

FOR MORE INFORMATION

- ▶ Parents as Caregivers: epilepsy.com/for-parents-caregivers
- ▶ National Institute on Aging Respite Care Resources: nia.nih.gov/health/what-respite-care

DIET & NUTRITION

The importance of diet has been reinforced in many ways. Research and individual experiences show improving the nutritional content of a person's diet can improve seizure control, brain health, and well-being in some people.

This factsheet offers information about diet and nutrition in general. For information about specific diet treatments for epilepsy, visit epilepsy.com/dietary-therapy. Special epilepsy diets should only be undertaken with a nutritionist and physician.



What does eating healthy mean?

- ▶ Eating properly prepared, nutrient-dense, whole foods
- ▶ Enjoying food in a positive, healthy environment
- ▶ Minimizing processed foods and refined sugars
- ▶ Eating recommended portions, ensuring fruit and vegetable intake (choosemyplate.gov)



What are nutrient-dense foods?

Nutrient-dense foods have lots of nutrients such as vitamins and minerals, fiber, lean protein, and unsaturated fats but are not high in calories. These foods are essential for a healthy brain as well. Some examples are:

- ▶ Fruit and vegetables
- ▶ Whole grains
- ▶ Low fat dairy products such as milk or yogurt
- ▶ Fish, such as salmon
- ▶ Lean meat



Why are diet and nutrition important for people with epilepsy and their caregivers?

Studies show that eating whole foods low in sugar have a positive impact on:

- ▶ Seizure control
- ▶ Depression/anxiety
- ▶ Other conditions related to epilepsy

DIET & NUTRITION

For caregivers, eating a healthy diet can help to:

- ▶ Prevent illness
- ▶ Increase energy
- ▶ Balance moods

Remember, caring for yourself is part of being a good caregiver.

Note: Folate (folic acid) is important for everyone's health. It can also protect unborn babies against serious birth defects. Women taking seizure medicines who could possibly become pregnant should talk to their health care provider about taking folic acid each day.

Can I make these changes on my own?

It's always a good idea to talk with your health care team before making any major changes. They may have specific diet recommendations for you. If you're having trouble getting started or sticking to changes in your diet, consult a nutritionist. They can assess your needs and any problems you may be having. They can also help develop meal plans, monitor your progress, and provide support along the way.



How can I begin?

- ▶ **Minimize:**
Start by removing the processed, sugary, boxed/packaged foods in your home.
- ▶ **Stock Up:**
Stock up your kitchen with whole and unprocessed foods.
- ▶ **Community:**
Surround yourself with a community that supports your healthy eating habits. Let people in your community and your medical team know about the dietary changes you're making and encourage them to join you, support you, and help keep you accountable.

It may be hard to change old habits and how you eat. But the longer you stick with it, unhealthy food cravings will subside and you will feel better than ever.

FOR MORE INFORMATION:

- ▶ Diet and Nutrition: epilepsy.com/healthy-eating
- ▶ Dietary Therapies: epilepsy.com/dietary-therapy
- ▶ Charlie Foundation: charlifoundation.org

STRESS MANAGEMENT

What is stress?

Stress is your body's response to change, especially a demand or a threat. Stress can be triggered by environmental, physical, or emotional changes—they can be positive or negative changes too. Sometimes stress can be good.

- ▶ Stressful times can be exciting, like the birth of a child or a job promotion.
- ▶ It creates energy for meeting challenges, such as moving to a new neighborhood or making new friends.
- ▶ At times, stress can help a person focus and get motivated.
- ▶ It can push a person to meet deadlines and complete important tasks.
- ▶ It can even help a person respond to danger.

And sometimes stress can be bad.

- ▶ If you have too much stress or have trouble coping, you can feel overwhelmed.
- ▶ Your body's response to stress produces mental, physical, or emotional symptoms.
- ▶ It can affect your sense of well-being, relationships, and other important areas of your life.
- ▶ It also can cause you to feel inadequate and lower your self-esteem.
- ▶ Too much stress can be a trigger for seizures.

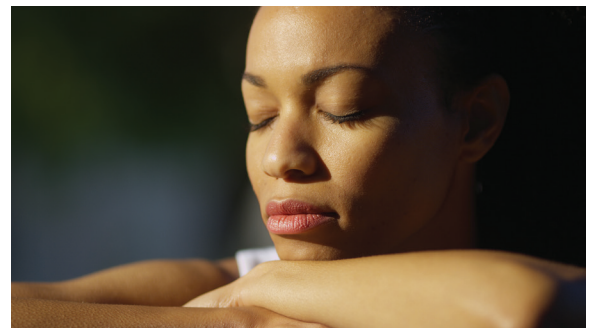


Why is stress management important for people living with epilepsy and their caregivers?

Everyone—people living with epilepsy, family, friends, and other caregivers—feels stress at times. Stress is a normal part of life, but chronic stress is bad for anyone's brain.

For many people living with epilepsy, stress can trigger seizures. Seizures may be more likely to happen at times of stress or may be worse or different than usual.

Living with epilepsy and unpredictable seizures can cause stress too. And people who are taking care of or helping a person with seizures may be susceptible to too much stress as well.



STRESS MANAGEMENT

What can I do to manage stress?

Managing stress is critical to your emotional and physical health. It contributes to your feelings of well-being, improves your social relationships, increases your productivity, and lifts your mood.

Here are some strategies to try.

Assess Your Stress

- ▶ **Study your life stressors.** Begin by tracking your stress. When do you notice it? How often do you feel signs of stress? What do you do when you feel stressed? How do you usually cope with stress?
- ▶ **Keep a journal.** Look at what is going on in your life. If you are feeling angry, anxious, or depressed about people or situations in your life, write about them. This may help you understand these feelings and what's causing them. You may gain insight and find better ways to cope.
- ▶ **Track your mood and stress.** You can use the Foundation's *My Seizure Diary* (diary.epilepsy.com), other digital tools, or a paper seizure diary to help you see patterns with seizures.

Use Cognitive Strategies

- ▶ **Steer clear.** Sometimes it is best to walk away from situations or relationships creating stress in your life. If you can't avoid something, try changing your approach and how you react. This may calm the situation and how you feel.
- ▶ **Breathe.** Try deep breathing when in a stressful situation. Counting to 10 and taking a time out helps too. The extra time gives you a chance to think more objectively and not overreact.
- ▶ **Manage your time.** A daily routine can help you juggle the many demands on your time. Set priorities, pace yourself, and avoid procrastination so you're not rushed. Find time to do the things you enjoy, too—not just the “must do” things.
- ▶ **Meditate.** Mindfulness or meditation can help relax you and restore your inner calm.
- ▶ **Use positive thinking techniques.** Is your life glass half full or half empty? Practice flipping the stress hourglass and see if this gives you a different perspective. Find the silver lining in stressful circumstances. For example, some negative situations can help you learn or improve.



STRESS MANAGEMENT

- ▶ **Learn skills to deal with stress.** Read or watch videos on stress management and discover new ways of coping.
- ▶ **Celebrate your success.** Find ways to see your progress. It takes effort to change old habits, but as you do, take a minute to measure your success and pat yourself on the back.

Use Physical Strategies

- ▶ **Exercise.** Build physical activity into your life. Find a routine that suits you such as walking, sports, yoga, pilates, tai chi, or gardening. Exercise has proven health benefits not only for your stress level, but also your mood, sleep, and overall health.
- ▶ **Sleep.** Your body needs to re-energize each day. Sleep helps you recover from all the demands on your time and energy. It helps you think more clearly too. Getting quality sleep and enough sleep are important.
- ▶ **Eat healthy foods.** Nutritious foods will give you energy. Find ways to build more nutritious foods into your diet. Try to avoid too much sugar, alcohol, or processed foods.
- ▶ **Listen to music.** This can be soothing or lively and distracting. Dancing to music is also a good way to boogie your stress off.
- ▶ **Take a warm shower.** A warm shower before bedtime can help you relax and be ready to sleep. Be careful to observe bathroom safety tips—people with uncontrolled seizures should take showers instead of baths.
- ▶ **Make some art.** Skill level doesn't matter. Sketching, painting, pottery, crafts, or even coloring benefit all ages. Consider taking an art class.
- ▶ **Get regular massages.** These can relax the tension stored in your body.
- ▶ **Go outside.** Take a break from the indoors and get some sunshine. Connecting with nature has proven benefits to feeling happier and calmer. Being outside and activities like bird watching may help.



Use Emotional Strategies

- ▶ **Smile.** Even if you don't feel happy, smiling can improve your mood and help you feel more relaxed. Other people may respond more positively to you too.
- ▶ **Manage your anger.** Take classes or read about anger management and conflict resolution. Consider professional help if your anger is interfering with your relationships.
- ▶ **Engage in pleasurable and calming activities.** Make a list of things you enjoy that help you to de-stress and do these regularly.
- ▶ **Find support.** Talking to a family member, friend, or colleague for support can be helpful and reassuring. They may have suggestions that are new to you.

Seek Help

- ▶ **Talk about it.** Talk about how you feel and how the unpredictability of seizures affects your day-to-day life.
- ▶ **Seek professional help.** Counseling from a mental health provider can teach you about stress management. A counselor can help you work on things that may be causing your stress, such as marital problems or concerns about your child or work.
- ▶ **Get the best seizure control possible.** Work closely with your health care team. Seek help from an epilepsy center to explore all treatment options.
- ▶ **Connect.** Find people who share your interests and who bring out the best in you.
- ▶ **Join the epilepsy community.** Reach out to your local Epilepsy Foundation. Join the forums and chat on epilepsy.com or social media. You will find people who understand and care about your well-being.
- ▶ **Join a support group for people with epilepsy.** Consider joining a support group for stress management, parenting, therapy, or other interests.

FOR MORE INFORMATION

- ▶ Stress and Wellness: epilepsy.com/stress-and-wellness
- ▶ Managing Seizure Triggers: epilepsy.com/managing-seizure-triggers

SLEEP

What is sleep?

Sleep is the process your body uses to recover from the wear and tear of daily living. Sleep is a necessary part of life. It is essential for mental and physical health, quality of life, and safety. You could pursue a healthy lifestyle by eating a healthy diet, exercising regularly, and finding strategies to reduce stress. But, without good quality sleep, your health is at risk.



While most people know the value of sleep, many don't make sleep a priority or the sleep they get isn't good quality sleep. The key to good health is knowing how sleep affects you, how much sleep you need, and ways to get better sleep.

Why is sleep important for people with epilepsy, their families, and caregivers?

Sleep and epilepsy are closely connected.

- ▶ Sleep can affect the timing, number, and severity of seizures.
- ▶ Not enough or poor quality of sleep is a common seizure trigger for many people.
- ▶ Some epilepsy syndromes are highly related to sleep and may be called sleep-related epilepsies. For example, some seizures may happen only at night—shortly after falling asleep, during certain sleep stages, or upon waking up.



- ▶ Seizures at night interrupt the quality of sleep often leaving people feeling sleep deprived.
- ▶ Epilepsy can worsen your ability to sleep and can also make sleep disorders worse.
- ▶ Not sleeping well at night can make you feel poorly during the day.
- ▶ Some seizure medicines also affect sleep. Some may make people sleepier. Others may lead to problems falling or staying asleep.

People with problems sleeping should talk to their epilepsy providers as well as their primary care providers to sort out possible causes of sleep difficulties.

Caregivers and Sleep

If you are a caregiver for someone living with epilepsy, it is very important you make healthy sleep a priority for yourself. Parents of children with epilepsy generally do not get enough sleep. For example:

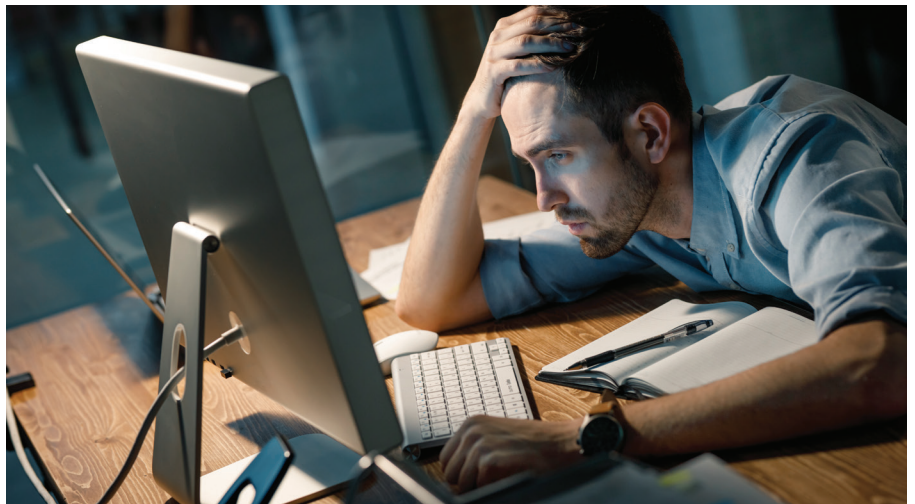
- ▶ You may worry about your child or family member at night.
- ▶ You may be woken up by seizures and not get enough sleep.
- ▶ You may sleep in your child's room to be there in case they have a seizure.

If your child or loved one has epilepsy, look at your own sleep habits. Are you getting enough sleep? Is it broken up? Are you tired during the day? If you or your partner are having trouble sleeping, talk to a health care provider about ways to address the problem.

Effects of Poor Sleep

Practicing good sleep habits is important for both physical and mental health. A good night's sleep can make you more productive and affect how you feel during the day.

- ▶ Daytime sleepiness can cause many problems, including car accidents, anxiety, attention problems, short tempers, home and workplace injuries, or overeating.
- ▶ Long-term sleep deprivation can lead to high blood pressure, heart attacks, stroke, obesity, depression, and other mood disorders.



Some of these problems may be related to medication side effects, other health problems, and life challenges related to epilepsy and seizures. Always check with your health care provider if any of these problems happen.

How much is enough sleep?

Sleep needs are different for each person and can change as you age. The key is to get the right amount of sleep on a consistent basis. More sleep is not always a good thing. According to the National Sleep Foundation, the sleep recommendations for each age group are as follows:

SLEEP

AGE	RECOMMENDED	MAY BE APPROPRIATE	
Newborns: 0-3 months	14 to 17 hours	11 to 13 hours	18-19 hours
Infants: 4-11 months	12 to 15 hours	10 to 11 hours	16 to 18 hours
Toddlers: 1-2 years	11 to 14 hours	9 to 10 hours	15 to 16 hours
Preschoolers: 3-5 years	10 to 13 hours	8 to 9 hours	14 hours
School-aged Children: 6-13 years	9 to 11 hours	7 to 8 hours	12 hours
Teenagers: 14-17 years	8 to 10 hours	7 hours	11 hours
Young Adults: 18-25 years	7 to 9 hours	6 hours	10 to 11 hours
Adults: 26-64 years	7 to 9 hours	6 hours	10 hours
Older Adults: ≥65 years	7 to 8 hours	5 to 6 hours	9 hours

How do I get a good night's sleep?

No matter how much sleep you need, there are several steps you can take to improve your sleep habits. Here are some tips to get a good night's sleep.

- ▶ Set a realistic time for bed and stick to that schedule.
- ▶ Follow a relaxing routine at the end of the day to shut down and de-stress.
- ▶ Turn off electronics an hour before bed and remove all electronics/blue light from your bedroom.
- ▶ Get some sun during the day to jumpstart the production of melatonin, a hormone that regulates your sleep and wake cycles.
- ▶ Keep the bedroom dark, quiet, and cool for the best sleep (between 60–67 degrees Fahrenheit).
- ▶ Use fans or humidifiers to create white noise and soothe you.
- ▶ Create a sleep-friendly bedroom with a comfortable mattress and pillow.
- ▶ Get plenty of exercise during the day.
- ▶ Avoid large meals right before bedtime.
- ▶ Avoid stimulants and alcohol in the evening.
- ▶ If you must use sleep aids, talk to your health care provider.

What if these tips don't help?

If you have a sleep problem that does not get better by improving your sleep habits, talk to your health care provider.

- ▶ He or she may suggest an evaluation to test for a sleep disorder and may prescribe medication or devices to improve sleep.
- ▶ Tests may be needed to see if you are having seizures at night.
- ▶ Seizure medicines may need to be adjusted. Don't make changes on your own. Suddenly stopping or changing your seizure medicine can cause more problems.
- ▶ Changes in mood, such as depression and anxiety, can also cause sleep problems.
- ▶ Talking to a mental health provider may help sort this out. Sometimes counseling or behavior changes help mood and sleep.
- ▶ If problems persist, medication for mood may be needed.

Whatever the cause, keep working on good sleep habits and staying healthy.

FOR MORE INFORMATION:

- ▶ Wellness and Sleep: epilepsy.com/sleep-and-wellness
- ▶ Sleep and Epilepsy: epilepsy.com/challenges-sleep

SOCIAL RELATIONSHIPS

What are social relationships?

Social relationships are the connections we have with other people: friends, family, and loved ones. Relationships build our communities of support.



Why are social relationships important for people with epilepsy, their families, and their caregivers?



We all know epilepsy is more than seizures, and it takes a toll on quality of life. A number of factors can affect your quality of life, and sorting through these can be overwhelming. However, one factor has been consistently identified as the single best predictor of happiness and well-being—the quality of our social connections and interpersonal relationships.

Friends and family provide you with a support network—people who can help you physically and boost you emotionally. Studies have also shown that having friends can lead to better health outcomes and help you live longer.

How can epilepsy affect a person's social relationships?

- ▶ Seizures can be socially isolating.
- ▶ Fear of having a seizure in public is a common worry.
- ▶ Dealing with daily challenges of epilepsy can be exhausting and leave you with little time and energy for family and friends.
- ▶ Transportation is challenging. If you can't drive, it limits your ability to go out and socialize.
- ▶ Fear of injury may make you reluctant to take part in some social activities.
- ▶ Stigma can present a barrier—you may worry what others think of you and how you may be accepted.
- ▶ Other disabilities can present challenges too, such as difficulty thinking, remembering, or even moving around.
- ▶ Chronic stress and worry affect how we relate to others. They can also lead to depression and anxiety.

What can I do to improve my social relationships?

Understand your family relationships

Epilepsy can put a strain on families in many ways. Everyone is in it together, but they experience it differently. A family member may feel helpless or angry because they can't make the seizures stop and they feel as though their lives have changed. They may be scared and try to protect their family member who has seizures. But the person with seizures may feel overprotected and want more space and independence. They may be afraid that they are a burden to their family and pull away.

- ▶ Talk about how each family member feels. When reactions aren't addressed or talked about, relationships between family members can get strained.
- ▶ Families can be a great source of support for someone with epilepsy, but it might take some work. Encourage all members of your family to learn as much as they can about epilepsy.

Find a support network

Having epilepsy can be upsetting and make you feel isolated and alone. If you have epilepsy or are a family member or friend, the good news is that you're not alone. Chances are there is a community of people in your area going through the same challenges that you are.

- ▶ Look for a support group from your local Epilepsy Foundation (epilepsy.com/local).
- ▶ Ask your doctor or other health care professionals for help.
- ▶ Check with the nearest epilepsy center to see if they have a support group or can connect you with other families.
- ▶ Connect with others on our online community at epilepsy.com/connect.

Reach out to friends

It's okay to feel nervous about telling other people about your epilepsy. You might be worried that they'll start treating you differently or that they won't handle it well. But chances are, they will surprise you. And you never know, you might discover that they have epilepsy too or that they have a relative or friend who does.

- ▶ You don't have to tell everyone as soon as you're diagnosed. Tell those closest to you as soon as you can. You don't have to tell all the details either. Decide what you are comfortable with and why they might need to know.
- ▶ Try not to hide your epilepsy—that can be dangerous. If you have a seizure, you want to make sure others are prepared and will know what to do. If you need to ask for rides or need assistance, you might find it's easier to ask for help when people know the reason.



SOCIAL RELATIONSHIPS

How do I start talking about epilepsy with my friends?

Where you talk about epilepsy and how you bring it up may affect how others respond to you. It's best to pick a time and place when you're comfortable and where you won't be interrupted.

Try to stay matter-of-fact and positive. Epilepsy is only part of who you are and isn't anything to be ashamed of. If you act like your epilepsy isn't a big deal, your friends will just take it in stride.

Here are some opening lines that may help:

- ▶ “You know how I'm always wearing this necklace? It's a medical alert necklace because I have epilepsy.”
- ▶ “Remember that movie we watched in health? I have seizures too, but mine are a little different.”
- ▶ “Did I ever tell you why I take medicine every day? I have epilepsy, and I take medicine so I don't have seizures.”
- ▶ “Remember yesterday, when I was acting strange? That was actually a seizure.”

What do I say?

When you tell people you have epilepsy, talk about the type of seizures you have and what they should do if you should have a seizure. People may want to know if your seizures hurt, what they feel like, or if there's anything they can do to stop your seizures. They may also worry that epilepsy is contagious or that they might be doing something to cause your seizures.

- ▶ Try to reassure people that the seizures aren't contagious or caused by anyone.
- ▶ If you have photosensitive epilepsy, you might want to mention flashing lights can be a seizure trigger for you.
- ▶ Print some information from our website (epilepsy.com) or have some Epilepsy Foundation brochures or handouts to give the person.



When you tell people you have epilepsy, you may face a lot of questions. Depending on their culture and age, some people may have very different perceptions about epilepsy. In other instances, you might learn the person already knows about epilepsy. It could take a few days for the person to process what you've told them and to begin asking questions. Try to be patient—you've had longer than they have had to learn about epilepsy.

It's important to remember that you deserve to be treated well and that you will find friends who appreciate you for who you are—epilepsy and all.

FOR MORE INFORMATION:

- ▶ [Epilepsy and social concerns: epilepsy.com/challenges-social](https://www.epilepsy.com/challenges-social)
- ▶ [Seizure first aid and safety: epilepsy.com/firstaid](https://www.epilepsy.com/firstaid)