

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



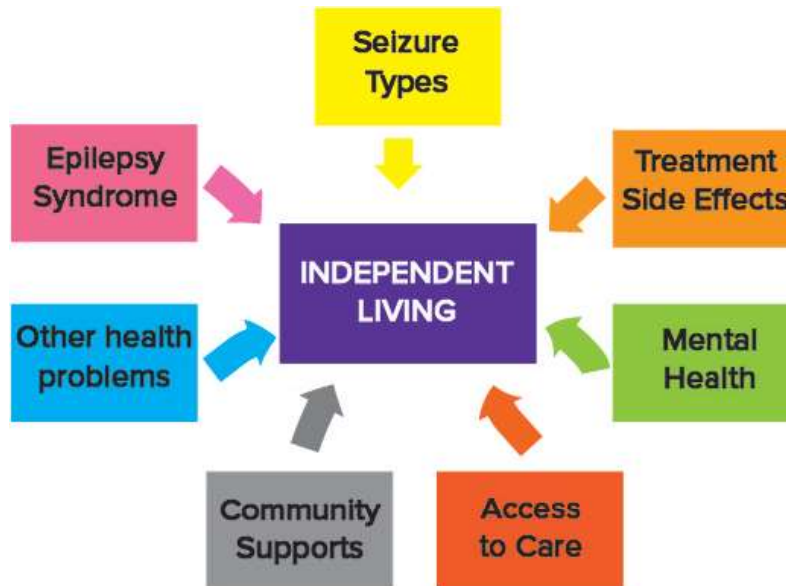
Some facts about independent living and epilepsy:

- ▶ 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.

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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

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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.

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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