

Transitioning into adulthood:

a checklist for caregivers whose loved ones have LGS



Are you caring for someone who has seizures associated with **Lennox-Gastaut syndrome (LGS)**? Many people find it helpful to plan ahead to prepare for their child's transition to adulthood. Use the checklist below to make sure you're taking every step to help your child transition to adult care.

Legal

Obtain *legal guardianship*

In the U.S., a person becomes their own guardian once they turn 18. For people living with LGS, their parent or caregiver may need to file for guardianship.

- This allows the caregiver to continue making personal and healthcare decisions for their child throughout adulthood
 - » Note that there are different types of guardianships available, and the rules that govern them vary between states

Examples of guardianship for children with LGS may include:

- General guardianship: the guardian is given full responsibility for the individual covering all their needs, such as medical, financial, and personal
- Permanent guardianship: the guardian is given indefinite or long-term legal responsibility for the child

Talk to legal counsel in your state for advice.

Consult *legal resources*

- Special Needs Attorneys and local government resources can help navigate the legal requirements and issues faced by special needs adults

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Legal

Apply for Social Security benefits

Consider applying for your child to receive Supplemental Security Income (SSI)

- People younger than 18 years old may qualify for Supplemental Security Income (SSI) if their physical or mental condition and family income meet the SSI requirements
- When children turn 18, they may be able to receive Social Security Disability Insurance (SSDI) if they meet the eligibility criteria

To learn more about the details for receiving Social Security benefits for children with disabilities, please call Social Security at 1-800-772-1213 or visit <https://www.ssa.gov/pubs/EN-05-10026.pdf>

Get a State ID card (*non-driver ID*)

As they grow to age 18 and beyond, your child will most likely require some kind of photo ID. A state-issued ID is a great solution for people who are unable to get a driver's license and can prove useful when:



Boarding an
airplane



Making certain
purchases



Getting a job



Applying for
support services

Get an ID for your loved one by visiting your local Department of Motor Vehicles.

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Medical

Check *seizure medication*

Make sure your loved one's seizure medication is still providing effective treatment as they transition to adulthood.



Dosing

Dosing for BANZEL® (rufinamide) is different for children and adults. Once your child turns 17, his or her doctor may need to adjust the dose of BANZEL.



Schedule

Many people with LGS must follow a complex treatment schedule. This may require multiple medications taken at different times of the day, with and without food. Ask your child's doctor if their schedule can be simplified as part of his or her transition to adulthood.



Taking medication as prescribed

As they grow more independent, your child may have trouble (or even resist) sticking to their medication schedule on their own. Have a plan in place to make sure all medicines are taken as directed.

Find *the right doctor*

Choosing the right doctor is crucial to your child's health. From neurologists to dentists, you'll want to find a doctor who has experience treating people with seizures.



As your child grows older, his or her pediatric neurologist and dentist may recommend moving your child to an adult neurologist and non-pediatric dentist.



Ask the pediatric doctor and dentist if they are willing to consult with their adult counterparts to pass along additional information about your child's LGS seizures and treatment history.



On your first visit to your new doctor, take your old files and test results with you. This will help educate the doctor on your loved one's history and status. It also helps ensure that tests that have already been done won't be repeated.

Indication

BANZEL (rufinamide) is a prescription add-on medication approved for the treatment of seizures associated with Lennox-Gastaut Syndrome (LGS) in pediatric patients 1 year of age and older, and in adults.

Selected Safety Information

Patients with a history of Familial Short QT syndrome should not be treated with BANZEL. Talk to your healthcare provider if you are unsure if this affects you or your loved one. BANZEL has been shown to reduce the QT interval. Caution should be used when administering BANZEL with other drugs that shorten the QT interval.

Please see the Important Safety Information on page 6 to learn about risks associated with BANZEL.

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Personal

Develop an Individual Service Plan (ISP)

ISPs include information about the resources, requirements, and support that a person needs. These plans help ensure that the best interests of the individual are being met.



States may provide home and community-based services (HCBS) waivers for eligible individuals looking for long-term care and in-home support. Check with your state agency responsible for administering HCBS waivers for more information.

Consider a group home

Some children with LGS are able to move into group homes when they get older. This allows them to live with some degree of independence and meet other people with LGS. If your loved one is able to join a group home, consider the following:



Create a seizure action plan:

It's critical to have a "seizure action plan" in place so the staff knows what to do when one occurs. It should include information such as:

- *Basic seizure first aid and comfort techniques*
- *When to call a doctor/go to an ER, along with emergency care instructions*
- *A place to record seizure details*
- *Who to contact in case of an emergency, and the best way to be reached*
- *Approved medication list with dosing and side effects information*



Create a medication schedule:

For non-emergency, everyday use, it's also helpful for the staff to have clear, written instructions about your loved one's medications. It should include information such as:

- *Which medications your loved one is taking*
- *The dosing schedule*
- *Whether they need to be taken with food*
- *Possible side effects and how they can be managed*
- *What to do if they miss a dose*

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Personal



Get help *finding employment*

Having a job can help a person feel a sense of purpose and find rewards through accomplishment. Despite its disabling effect, many people with LGS have skills and abilities that may enable them to hold some type of job (as long as it can be tailored to fit their needs).



Even if your child has experienced cognitive loss due to their LGS, there still may be opportunities for them to hold simple jobs or take part in volunteer activities.

Contact your local epilepsy foundation office at [Epilepsy.com/affiliates](https://www.epilepsy.com/affiliates) to learn about potential job opportunities for people with LGS.

Remember:

Treatment with BANZEL® (rufinamide) may need to change as your child becomes an adult. Talk to your doctor if you have any questions.

Selected Safety Information

All medications to treat seizures, including BANZEL, may cause suicidal thoughts or actions in a very small number of people, about 1 in 500. Call your healthcare provider right away if you or your loved one experiences new or worsening symptoms of depression, unusual changes in mood or behavior, thoughts or actions about suicide or self-harm, aggression, agitation, anger, anxiety, or irritability.

Please see the Important Safety Information on the next page to learn about risks associated with BANZEL.



Important Safety Information

- Patients with a history of Familial Short QT syndrome should not be treated with BANZEL. Talk to your healthcare provider if you are unsure if this affects you or your loved one. BANZEL has been shown to reduce the QT interval. Caution should be used when administering BANZEL with other drugs that shorten the QT interval.
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- Use of BANZEL has been associated with side effects such as sleepiness or feeling tired, difficulty with coordination, dizziness, and problems with walking or movement.
- Do not drive, operate heavy machinery, or do other dangerous activities until you know how BANZEL affects you. BANZEL can slow your thinking and motor skills.
 - Alcohol, in combination with BANZEL, may increase or worsen these side effects.
- Call your healthcare provider if you or your loved one experiences a rash. This can be a sign of a more serious condition, such as multi-organ hypersensitivity reaction.
- You or your loved one should take BANZEL only as prescribed. Do not stop taking BANZEL without first talking to your healthcare provider. Stopping BANZEL suddenly can cause serious problems.
- Tell your healthcare provider about all the medications you or your loved one takes, including prescription and non-prescription medications, vitamins, and herbal supplements. Using BANZEL with certain medications can affect each other, causing side effects.
- In studies, the most commonly observed ($\geq 10\%$) side effects with BANZEL were headache, dizziness, feeling tired, sleepiness, and nausea.

Important Information for Women

- BANZEL may make hormonal contraceptives (birth control pills) less effective. Additional nonhormonal forms of birth control are recommended when using BANZEL.
- Healthcare providers should be informed if patients are pregnant or planning on becoming pregnant.
- Also, BANZEL is likely to be passed through breast milk to the baby and could cause serious side effects in the baby. A decision should be made whether to discontinue nursing or discontinue the drug, taking into account the importance of the drug to the mother.
- Patients who are pregnant are encouraged to enroll in the North American Antiepileptic Drug Pregnancy Registry. This can be done by calling the toll-free number 1-888-233-2334. Additional information about the registry can be found at www.aedpregnancyregistry.org.

Indication

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There are risks associated with the use of BANZEL that you should know about. We encourage you to talk to your healthcare provider about these risks.

Please see BANZEL full Prescribing Information, including Medication Guide, at www.BANZEL.com/PrescribingInfo, and discuss it with your doctor or healthcare professional.

To report suspected adverse reactions, contact Eisai Inc. at 1-888-274-2378 or the FDA at 1-800-FDA-1088 or www.FDA.gov/medwatch.

For more information about BANZEL and LGS, visit BANZEL.com.

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