

Supported Decision-Making Tool for LGS

FOR HEALTH CARE PROFESSIONALS & CAREGIVERS

| What Supported Decision-Making Is

Supported decision-making is a structured approach to help individuals with Lennox-Gastaut syndrome (LGS) participate in their own care decisions to the greatest extent possible, even when communication or cognitive limitations are present. The patient keeps agency; supporters help interpret information, express preferences, and ensure that decisions reflect the patient's values. Supported decision-making is also increasingly recognized as an alternative or complement to guardianship, allowing individuals to retain their rights while still receiving guidance from trusted supporters. Health care professionals should continue to follow local laws, institutional policies, and any existing guardianship or power-of-attorney documents when obtaining consent for medical treatment.

| When Supported Decision-Making Is Useful in LGS

Use when the person:

- Has limited verbal communication or uses alternative communication methods
- Needs help understanding treatment options or risks
- Benefits from visual, simplified, or step-based explanations
- Is transitioning from pediatric to adult care and needs increased involvement
- Is not their own guardian but still has preferences that must be respected
- Is making or revisiting decisions about where they live, daytime programs, or supports as they move from school-based services to adult day programs or group homes

| Who Can Be a Supporter

- Family caregivers
- Group home or residential staff
- School or day-program staff
- Case managers or social workers



- Clinicians familiar with the patient's communication style
- Communication professionals (e.g., speech-language pathologists) who can help establish or support communication tools such as augmentative and alternative communication (AAC) devices, picture boards, or yes/no systems

Supporters must be people the patient trusts and who understand their communication cues.

When possible, supporters should be consistent over time so they can recognize patterns in the person's responses and preferences.

How to Use Supported Decision-Making

1. Present Information Accessibly

Use methods suited to the patient:

- Simple, concrete language
- Pictures, visual aids, or yes/no cards
- Choice boards or eye gaze options
- Use the individual's preferred communication device or app (if they have one) to present options (e.g., icons on a tablet), and keep communication consistent with their usual method
- Short, stepwise explanations rather than abstract discussions

Examples of accessible formats:

- "This medicine helps with drop seizures."
- "This option may make you sleepy. Do you like or not like feeling sleepy?"

2. Identify the Patient's Preferences

Supporters help the patient show preferences by observing:

- Facial expressions, gestures, and eye gaze
- Acceptance/rejection behaviors
- Signs of stress versus comfort
- Engagement or withdrawal when options are discussed

Document any consistent patterns:

- "Calm and engaged when drop seizures decrease"
- "Avoids discussion of medication changes when anxious"



3. Weigh Options Together

Supporters help the patient understand choices by comparing:

- Benefits (e.g., fewer drop seizures, improved sleep)
- Possible risks (e.g., sedation, behavior changes)
- Impact on daily routines or quality of life (e.g., choice of day program, preferred activities, privacy and sleep schedule, social interactions, or noise level in a group home)

Use clear prompts:

- “Do you choose Option A or Option B?”
- “Do you want to keep things the same or make a change?”

4. Make the Decision with the Patient

The final decision should reflect:

- The patient’s communicated preference
- Clinical recommendations
- Caregiver and supporter insights
- Safety considerations

Example Scenario

Maria is a 17-year-old with LGS who is nonverbal. Her neurologist is considering adjusting her medication. Using supported decision-making, the team presents Maria with two options using simple picture cards. They observe that when shown the option that may cause drowsiness, Maria frowns and turns away, but she smiles and leans toward the alternative option that is expected to improve alertness. The caregiver and clinician interpret this as Maria’s preference, and together they decide to try the alertness-preserving option while closely monitoring for side effects.

Supporters ensure the patient’s preference is heard and included, even if legal guardianship exists.

Importantly, supporters should balance the individual’s preferences with their health and safety needs. Some decisions (such as treatments with significant risks) may require more guidance, but the person’s feelings and perspectives should still be acknowledged and included.

5. Document and Review Regularly

Record:

- Who the supporters are
- What communication methods work best
- How the patient expressed their preference
- The final decision and the reasons behind it

Revisit the plan:

- During medication changes
- After hospitalizations
- When seizure patterns shift
- During the transition to adult care

Quick Checklist for Supportive Decision-Making in LGS

Does the patient have a way to express preferences?

☐ Yes

☐ No

If no (or unclear), identify an effective communication method for the patient:

How does the patient show “yes” or “no”?

Who supports the patient in decision-making? List specific names and roles (e.g., “Jane Doe — mother; John Smith — group home staff.”)

How were options presented?

☐ Visual supports

☐ Eye gaze

☐ Simplified language

☐ Other: _____

☐ Choice board



What preferences did the patient show?

What decisions were made, and were the patient's preferences reflected?