

New guidelines aim to elevate comprehensive care for people with severe epilepsy

February 2 2024



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The National Association of Epilepsy Centers (NAEC) has developed updated guidelines that outline the comprehensive services and resources epilepsy centers should provide to improve quality of care for people

whose epilepsy is not well-controlled.

An [Executive Summary](#) of the 2023 Guidelines for Specialized Epilepsy Centers: Report of the National Association of Epilepsy Centers Guideline Panel was published online on February 2, 2024, in *Neurology*. The complete NAEC guidelines are published as an eAppendix on the journal's website.

Epilepsy is one of the most common chronic neurological conditions worldwide, with an estimated prevalence of 3.4 million in the United States. The condition, which causes recurring seizures, can be debilitating and life-threatening. It is associated with decreased quality of life and far-reaching socioeconomic implications.

About 30% of people with epilepsy have seizures that do not respond to medication. Uncontrolled seizures affect all aspects of life, such as the ability to learn or live independently. For these individuals, and those experiencing unacceptable side effects from anti-seizure medications, epilepsy centers can provide a more personalized level of care that improves a patient's total well-being.

"The field has changed significantly since NAEC issued its last guideline update over 10 years ago," said Fred Lado, MD, Ph.D., NAEC president, guideline panel co-chair, and regional director of epilepsy and professor of neurology at Zucker School of Medicine at Hofstra/Northwell in Hempstead, New York.

"In addition to advances in medicine, there has been a shift toward addressing overall well-being beyond seizure management. This includes care for comorbid conditions like anxiety and depression, enhanced communication between the patient and care team, and addressing health disparities in the epilepsy community. Expanded guidelines are also sorely needed to help centers and hospitals obtain the resources to

provide this level of comprehensive care."

The 2023 guidelines include 52 recommendations that span the range of services that should be part of high-quality epilepsy centers, including inpatient evaluation, therapeutic options, and outpatient chronic disease management.

The guidelines recognize the importance of multi-disciplinary care teams in coordinating the effort of different specialists working together to diagnose and treat patients.

For the first time, the guidelines recommend centers should:

- offer [genetic testing](#) and counseling.
- provide more education and communication for patients.
- give greater attention to special needs populations.
- employ a care coordinator who organizes and facilitates multidisciplinary care.
- provide mental health screening (anxiety, depression, and learning difficulties are much more common in people with epilepsy than the general population).
- address [health disparities](#) and inequities among the epilepsy patient population.

The recommendations were informed by an [evidence review](#) and reflect the consensus of a multidisciplinary panel of 41 stakeholders with diverse expertise, including patient and caregiver representatives, EEG technologists, [nurse practitioners](#), social workers, neurosurgeons, neuroradiologists, and others who support epilepsy center care.

"All recommendations quickly reached consensus despite there being such a diverse panel of stakeholders, which emphasizes that the recommendations reflect the important elements of health care services

that should be in place for an epilepsy center to provide the highest quality of care," said Susan Arnold, MD, guideline panel co-chair and a pediatric epileptologist at Yale University School of Medicine.

"We want to improve the quality of care across the board for people with epilepsy in the United States. NAEC has accredited centers that provide very high [quality of care](#), but each center has different strengths. By working together with these consensus guidelines, we can elevate the standards of quality care for all centers," said Dr. Arnold.

NAEC issued its first epilepsy center guidelines in 1990 and has developed updated guidelines every decade since. The 2023 guidelines are the first to be established on an evidence-informed, consensus-based process.

NAEC contracted with EBQ Consulting to develop evidence-based and trustworthy consensus-based statements that conform with established international standards. In the absence of strong evidence, recommendations were guided by consensus from the panels of experts and highlight areas of need for additional research.

"When patients feel their treatment options are limited, they don't have to accept 'good enough.' Epilepsy centers offer hope," said Dr. Arnold. "But epilepsy centers will need the resources to provide this comprehensive level of care. We hope the guidelines will help increase health insurer and institutional support and recognition of these recommendations."

As additional research becomes available, practice standards become established, and clinical knowledge grows, NAEC will continue to update the guidelines. Over time, these guidelines will inform NAEC's accreditation standards for [epilepsy](#) centers.

More information: Guidelines for Specialized Epilepsy Centers: Executive Summary of the Report of the National Association of Epilepsy Centers Guideline Panel, *Neurology* (2024). [DOI: 10.1212/WNL.0000000000208087](https://doi.org/10.1212/WNL.0000000000208087). [n.neurology.org/lookup/doi/10.1212/WNL.0000000000208087](https://www.n.neurology.org/lookup/doi/10.1212/WNL.0000000000208087)

Provided by Szabo Communications Strategies LLC

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