

How to navigate epilepsy care

July 7 2020, by Dr. Meriem K. Bensalem-Owen



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Despite the development of several new anti-seizure medications or anti-epileptic drugs over the past couple of decades, approximately 30 to 40% of epilepsy patients remain refractory—or resistant to medical treatment. In addition to the burden of having seizures, mortality in

epilepsy is a major public health concern. A recent study found a clear benefit of the care provided by a neurologist specializing in epilepsy, also referred to as an epileptologist, in relation to mortality outcomes.

What are the different levels of epilepsy care?

The National Association of Epilepsy Centers (NAEC) has defined 4four levels of care and accredits [epilepsy](#) centers through a rigorous process.

- Level 1 epilepsy care typically occurs at an emergency room or a primary care physician's office.
- Level 2 epilepsy care involves a consultation with a general neurologist.
- Levels 3 and 4 care takes place at specialized epilepsy centers. Level 4 centers provide the more complex forms of epilepsy evaluation and a wide range of surgical procedures.

When is time to ask for a second opinion when it comes to treatment for epilepsy?

In an effort to improve the quality of care delivered to [epilepsy patients](#) with an ultimate focus on improving outcomes, the American Academy of Neurology (AAN) developed quality measures, also known as metrics. One of the measures includes referral to a comprehensive epilepsy center. The NAEC website also provides guidelines for such referrals as well as a map for the closest epilepsy centers in one's region.

Physicians or any health providers should consider referring their patients to an epilepsy center if seizures continue despite treatment for more than one year. This treatment should include a trial of at least two anti-[seizure](#) medications. There are other situations where individuals

should seek care in an epilepsy center. Women of childbearing potential who are planning to conceive or are already pregnant should be referred to an epilepsy specialist or patients experiencing [side effects](#) from their medications affecting their [daily life](#).

Adults or parents of children who have uncontrolled seizures should not feel any hesitation or guilt about seeking a second opinion. Being formally evaluated at an epilepsy center is an important part of that process. Achieving seizure freedom, with minimal or no side effects from treatment, is priceless!

How can caregivers best prepare for a visit with an NAEC-accredited center?

Before the initial appointment, the University of Kentucky Level 4 accredited NAEC center provides an epilepsy focused questionnaire to patients and caregivers. Additionally, our coordinator obtains records and reports of prior tests from referring physicians' or healthcare providers' offices before the office visit.

The following are few tips to help prepare patients for the appointment:

- Define the expectation(s) of the visit.
- Make a focused list of questions and concerns to be brought up or discussed
- Be prepared to describe the seizure(s) or events(s) of concern, including duration and frequency.
- Some individuals may share a video (frequently taken on cell phones) of the seizures otherwise we rely on witnesses' description of the seizures.
- Know potential epilepsy risk factors or seizure-triggers (if any)
- Bring records of prior testing such as electroencephalogram

- (EEG), video-EEG studies, and brain imaging (MRI or CT scan)
- Special considerations, such as [family planning](#) for instance.
 - Enquire about community resources, including support groups and Epilepsy Foundation affiliates.
 - ... and, of course, take notes during the visit!

Provided by University of Kentucky

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