Quality of Life in Epilepsy

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Restrictions: Patients at risk for seizures should be warned that all environments or situations that could cause harm to the patient or others, should a seizure occur, must be avoided. Specifically:

- No working at "unprotected" heights, including roofs and ladders.
- No working around heavy machinery with moving parts.
- No construction equipment use.
- No use of manufacturing equipment, including, among others, fork lifts, heavy presses, and conveyor belt systems.
- Avoid known environmental triggers: heat, cold, humidity, dust, and fumes.
- Shower or bathe in minimal amounts of water in order to avoid drowning in case of loss of consciousness.
- Swim only when supervised by someone who is aware of seizure history and is capable of helping should a seizure occur.
- No cooking or working around open flames.
- NO DRIVING!

These restrictions stay in effect until released at the discretion of the provider or the stipulations of the state.

Driving: Without a doubt, the loss of driving privileges has the greatest overall impact on those with epilepsy. Each state has regulations and some leave the decision to the discretion of the provider. Driving restriction typically ranges between three and 12 months. Tennessee, for example, requires six months of seizure freedom, whereas Kentucky requires three months. The loss of driving means relying on others for transportation whether this is to school, work, shopping, or to go on a date! The loss of a license may mean the loss of employment for those that drive a truck or captain a boat for a living.

Commercial Truck Drivers: The restrictions are placed by the Federal Motor Carrier Safety Administration:

Current recommendations are that restrictions should be determined on an individualized basis. The nature of the seizure and risk of recurrence should be considered when determining fitness for specific job requirements.

- Persons with diagnosed epilepsy who are seizure-free and off medication for 10 years may be considered for licensure to operate a commercial vehicle.
- Onetime event thought to be nonepileptic and requiring no antiseizure medication will possibly allow for return to driving after six months of seizure freedom.
- Single unprovoked seizure with no recurrence may be considered for reinstatement following a five-year period off medication. A waiver to this determination may be made

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if the individual has a normal EEG and has been evaluated by a neurologist that specializes in epilepsy.
- Acute symptomatic seizures in the presence of acute structural insults to the central nervous system with low risk for recurrence; there should be no restriction after they have been seizure-free for two or more years off antiepileptic drugs.
- Persons that have undergone any procedure that penetrates the dura should not be considered eligible for commercial licensure [1].

Merchant Mariners Including Riverboat Captains: According to the US Department of Homeland Security and the United States Coast Guard under COMDTMOTE 16700.4, NVIC 04-08, Enclosure (8) Mariners, including commercial ship captains and riverboat captains, are controlled by the Coast Guard.

- Those mariners that have seizure(s) determined to be low risk of recurrence may be considered for a waiver to return to duty when they have been seizure-free and off medication for a minimum of one year.
- Those with seizures considered as high risk of seizure recurrence must be seizure-free for a minimum of eight years [on or off medication]. If they continue on medication their dose regimen must be stable for two years. If they are off medication, they must be seizure-free for eight years from the time they stopped the medication [2].

Aircraft Pilots: Neurological disorders: epilepsy, seizures, stroke, paralysis, etc. The applicant should provide history and treatment, pertinent medical records, current status report, and medication. The Examiner should obtain details about such a history and report the results. An established diagnosis of epilepsy, a transient loss of control of nervous system function(s), or a disturbance of consciousness is a basis for denial no matter how remote the history. Like all other conditions of aeromedical concern, the history surrounding the event is crucial. Certification is possible if a satisfactory explanation can be established.

Guide for Aviation Medical Examiners:

- A disturbance of consciousness without satisfactory medical explanation of the cause must submit all pertinent medical records, current neurological report, to include name and dosage of medication(s) and side effects. This requires Federal Aviation Administration (FAA) decision.
- Rolandic seizure must submit all pertinent medical records, current status report, to include name and dosage of medication(s) and side effect. Rolandic seizures may be eligible for certification if the applicant is seizure-free for 4 years and has a normal EEG.
  This requires FAA decision.
- Febrile seizure (single episode) must submit all pertinent medical records and a current status report if occurred prior to age 5, without recurrence and off medications for 3 years of issue.
  Otherwise, this requires FAA decision.
- Transient loss of nervous system function(s) without satisfactory medical explanation of the cause, e.g., transient global amnesia must submit all pertinent medical records, current status report, to include name and dosage of medication(s) and side effects. This requires FAA decision.
- Unexplained syncope, single seizure. An applicant who has a history of epilepsy, a disturbance of consciousness without satisfactory medical explanation of the cause, or a transient loss of control of nervous system function(s) without satisfactory medical explanation of the cause must be denied or deferred by the examiner. Consultation with FAA is required.
- Infrequently, the FAA has granted an authorization under the special issuance section of part 67 14 CFR 67.401 when a seizure disorder was present in childhood, but the individual has been seizure-free for a number of years. Factors that would be considered in determining eligibility in such cases would be age at onset, nature, and frequency of

seizures, precipitating causes, and duration of stability without medication. Follow-up evaluations are usually necessary to confirm continued stability of an individual's condition if an authorization is granted under the special issuance section of part 67 14 CFR 67.401 [3].

Common Seizure Triggers: Stress (positive or negative), fatigue, medication compliance, excessive alcohol use, and sleep deprivation. Positive stress usually relates to vacation time or cheerful events causing change of daily routine including change in food and alcohol intake, reduced sleep time, and changing time zones. Negative stress mostly relates to bad news and grief resulting in reduced sleep and poorer AED adherence.

Accommodations: According to the United States Department of Labor:

> A job accommodation is a reasonable adjustment to a job or work environment that makes it possible for an individual with a disability to perform job duties. Determining whether to provide accommodations involves considering the required job tasks, the functional limitations of the person doing the job, the level of hardship to the employer, and other issues. Accommodations may include specialized equipment, facility modifications, adjustments to work schedules or job duties, as well as a whole range of other creative solutions.
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> The Job Accommodation Network (JAN), a service of the Office of Disability Employment Policy (ODEP), provides a free consulting service on workplace accommodations [4].

Accommodations may be needed at work or school. Looking at the classic triggers, recommendations, and restrictions, it is simple to justify the accommodations often needed for the patient to function in their environment. The individual must understand that accommodations are not always possible.

A letter, worded carefully, should assure that the individual's needs are addressed without violating HIPAA rules, or requesting accommodations that are unreasonable.

Accommodations in the work place include the following:

- Minimize excessive stress,
- Limited work hours to 8–10 h/day,
- No third or midnight shift,
- No working at unprotected heights,
- No working around heavy moving machinery,
- Avoid environmental situations that are known triggers or that should a seizure occur could cause harm to the individual or others, and
- Provide assistive technology (AT) that can improve productivity of the individual coping with any cognitive issues.

College students with epilepsy should register with Student Health, protecting themselves should a need arise either physically or educationally. Seizure activity frequently escalates during the college years. Students in both high school and college may need assistance with recording lectures, extra time to prepare for examinations, and accommodations for missed classes secondary to seizure activity. Accommodations frequently requested include the following:

- Leniency on attendance.
- If seizures are active, they may have to rely on others for transportation.
- Seizures can result in an assignment not being completed or a class missed.
- All night study sessions are not possible due to risk of sleep deprivation.
- Avoidance of multiple examinations on the same day [frequently during mid-term and finals].
- Understanding that an assignment given one day and expected back the next might not be possible as it is imperative that the student gets adequate rest. All night study sessions can only produce negative outcomes.
- Short-term memory loss is not uncommon so "pop quizzes" will be difficult and the student may need other means of meeting the needed results.
- Assistance with reading, taking notes, or recording lectures.

- Single college room—allowing for adequate rest and no late night interruptions by roommates.

Other accommodations occasionally requested:

- Dogs/pets—both trained seizure dogs or companions that may stay in their dorm room or apartment;
- Request for single-level housing;
- Use of elevators when available rather than open stairwells;
- Access ride or other forms of discounted public transportation; and
- Use/purchase of wheelchairs, manual or motorized.

Disability: According to the Social Security Official Web site: [5]

SSR 87-6: TITLES II AND XVI: THE ROLE OF PRESCRIBED TREATMENT IN THE EVALUATION OF EPILEPSY

> POLICY STATEMENT: As a result of a modern treatment which is widely available, only a small percentage of epileptics, who are under appropriate treatment, are precluded from engaging in substantial gainful activity (SGA). Situations where the seizures are not under good control are usually due to the individual's noncompliance with the prescribed treatment rather than the ineffectiveness of the treatment itself. Noncompliance is usually manifested by failure to continue ongoing medical care and to take medication at the prescribed dosage and frequency. Determination of blood levels of anticonvulsive drugs may serve to indicate whether the prescribed medication is being taken. In a substantial number of cases, use of alcohol has been found to be a contributory basis for the individual's failure to properly follow prescribed treatment. In such cases, the individual's alcohol abuse should be evaluated. (See SSR 82-60, PPS No. 83, Titles II and XVI: Evaluation of Drug Addiction and Alcoholism.)

Documentation needed in the medical record:

EEG—Corroborating the nature and frequency of seizures;
Detailed description of typical seizure pattern including associated phenomena:

- Professional observation,
- Observation of a third party, and
- Description by the patient is not acceptable for social security requirements;

History of treatment, response and any recent changes;
Consistency in therapy:

- Attending regular clinic visits/ communications and
- Details regarding seizure history and responses to therapy;

Major motor seizures must be occurring more frequently than once a month—on medication;
Minor motor seizures must be occurring more frequently than once weekly in spite of being on prescribed treatment for at least 3 months;
Establish whether the seizures are due to factors beyond the individual's control or to noncompliance with prescribed therapy:

- Record of AED blood levels,
- Low levels must be explained,
- Noncompliance,
- Abnormal absorption or metabolism, and
- The dosage is not optimal.

Medications:
Insurance plans are becoming more complicated. A secondary program such as Medco/Express Scripts, CVS Caremark, Optum, EnvisionRxPlus, and many more generally processes prescriptions. This secondary program determines coverage and responses to appeals. Each program has its own formulary and appeals process. It is important to understand their requirements for coverage as often there are ways to successfully work around their roadblocks. These are only a few of the restrictions on prescriptions that may be encountered:

- generics only—often no appeal process,
- generics preferred—appeal process available,
- quantity limits—appeal possible letter of medical necessity,
- formulary/nonformulary,
- tiering/levels of coverage: anywhere from 2–4 tiers with the expense going up with each tier,

- tier exception—often requires letter of medical necessity requesting the medication be covered at a lower tier,
- percentage of cost,
- percentage of the total cost of the medication: 20, 50%,
- co-pay plus percentage,
- co-pay plus the difference in cost of generic versus nongeneric,
- controlling the dose by maximum milligrams allowed/day—not always associated with FDA recommendations:
  - use a mixture of strengths so that no one "medication" equals more than the allowed milligrams—Example,
  - needing 1000 mg but insurance only allows 600 mg, and
  - Use 3–200 mg tabs plus 4–100 mg tabs.
- limiting the number of tablets—this limitation is the most difficult to comprehend, it may require a maximum of two tablets per day, and it does not matter if they are 50 or 200 mg. It is important to understand this concept as the dose is increased.
- This same concept is involved when increasing doses. In order to get a larger dose, it may be necessary to use a combination of strengths merely to meet the number of tablets restriction.

The appeal process is often offered with particular programs and you must be able to demonstrate the step therapy and titration process.

Information that you should have ready anytime an appeal is submitted:

- all previously tried AEDs,
- dates used,
- reason for termination, and
- proof of previous use of the generic formulation.

Medications Affordability

Medications are frequently too expensive for the patient to afford. It is difficult to accept that the medication that is best for the patient is unavailable to them because of cost. There are programs that can assist patients with their medication costs. If the patient has no insurance or at least no medication coverage, they might be eligible for a pharmacy assistance program through the manufacturer. The same is true for those falling into the donut hole with Medicare. The easiest method to determine what programs are available to the patient is to access rxAssist.org. This Web site will advise of programs available and any necessary qualification. Discount cards are also available on many medications. The $4.00 programs offered by select pharmacies often provide a very limited number of AEDs. A program called RxOutreach has generic medications, including many controlled drugs at a price often cheaper than the usual insurance co-payment.

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