Quality of Epilepsy Care & What It Means To You

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Quality of Care Measures—Why are they important to you

- **Definition:**
  - The degree to which health services increase the likelihood of desired health outcomes of individuals and populations and which are consistent with current professional knowledge—*Institute of Medicine (IOM)*

- **Quality measures:**
  - Maximize your welfare
  - Improves the quality and length of your life
  - Produces better health outcomes for you

*Veterans deserve the highest quality of care*
Dimensions of Quality...

- **Technical quality:**
  - Your epilepsy care team has the technical skills to make the right decisions for you and perform care targeted for you.

- **Interpersonal quality:**
  - Your epilepsy care team can communicate with you, gain your trust, interact with you with empathy, honesty, and sensitivity to your concerns.

- **Amenities of care:**
  - Veterans Health Administration (VA) integrated care offers convenience and coordination of your health care and pharmacy benefits.

*Photo courtesy of Epilepsy Center of Excellence*
QUIET-VA: Quality Indicators in Epilepsy Treatment in the VA

- We developed quality of care measures (indicators) for People/Veterans with epilepsy in primary care and general neurology clinics.
  - http://www.biomedcentral.com/1472-6963/11/1/
- QUIET indicators are based on:
  - Scientific evidence
  - Expert opinion
  - Patient perceptions
- Find more information on Quality at Epilepsy.Com
  http://professionals.epilepsy.com/page/care_quality_measures.html
Definitions of Seizures & Epilepsy

- **Seizures**: sudden discharge of excessive electrical activity in the brain that cause
  - a change in behavior
  - Alterations in movement, awareness, consciousness, experience

- **Epilepsy**: a neurological condition that affects the nervous system.
  - Epilepsy is diagnosed after two or more unprovoked seizures.
  - A doctor should conduct physical and neurological examinations to determine the possible cause.

- [http://www.epilepsy.com/treatment/when_diagnosed](http://www.epilepsy.com/treatment/when_diagnosed)
Checking My Care for Epilepsy—
An easy to use checklist available to Epilepsy.Com

Download & print out
“Checking My Care for Epilepsy”

When you were first evaluated for seizures, did you have...

- A detailed discussion of your seizure history
- A review of other conditions that could cause or affect seizures
- A physical examination to rule out other causes of symptoms or medical problems that could affect seizures
- A detailed neurological examination to look for other neurological problems or findings that may help tell more about the type or location of seizures
- Blood and urine tests to look for medical problems that may affect seizures or occur as a result of a seizure
When you were first evaluated for seizures or diagnosed with epilepsy, if there was no obvious cause found, were you given...

- An EEG (electroencephalogram) to look at the brain waves for possible seizure activity or markers of seizures
- A brain scan, usually an MRI (magnetic resonance imaging) that looks at the structure of the brain for problems that may cause seizures or tell where they come from
- A referral to an epilepsy center or specialist
When you were first evaluated for seizures or diagnosed with epilepsy, were you given information on...

- Driving restrictions
- Safety including what to do if a seizure occurred and general safety instructions
- How to prevent injury, such as any equipment or aids that may help you stay safe
If your first seizure didn’t have any obvious cause,

but other tests were of concern* or if you or your caregivers or family felt the risk of more seizures was worth trying a medicine for seizures, did your doctor...

- Talk about how seizure medicines may help
- Talk about side effects or other risks of taking seizure medicine
- Offer or suggest that you take seizure medicine
- Describe if seizure medicine wasn’t needed and why
After you were diagnosed with epilepsy, did your doctor...

- Talk about the type of seizures you have
- Talk about what the diagnosis of epilepsy means
- Talk about how seizure medicines may help
- Explain possible side effects of seizure medicine
- Offer or suggest that you take seizure medicine
- Stress the importance of taking seizure medicine as prescribed and how to take them
After you were diagnosed with epilepsy, did your doctor...(2)

- Explain how lifestyle or other factors may affect seizure control and what to do
- Ask whether you use contraception
- Explain how seizure medicines may affect some forms of contraception & what to do
- Ask if you were planning on having children
- Talk about how seizures and seizure medicines may or may not affect having children
If you are over age 60 and started having seizures, did your doctor...

- Talk to you about the benefits and risks of starting seizure medicine after the first seizure or describe why seizure medicine may not be needed
- Talk about which seizure medicines may be most helpful for you
- Tell you which seizure medicines may affect other medicines taken for other reasons
- First recommend that you try a medicine that doesn’t interfere with other medicines
If you were started on seizure medicine after being diagnosed with seizures/epilepsy, did the doctor...

- Begin you on one medicine
- Talk to you about other medicines you take
- Talk about ways to lessen the chance that the drugs would affect each other
At follow-up appointments, did the doctor...

- Ask how often you had seizures and what kind
- Ask about side effects of medicines
If the first treatment did not work to stop seizures ...

Were you referred to a Neurologist to clarify the diagnosis or type of seizures

☐ Yes
☐ No
If you continued to have seizures for a year after being evaluated by a neurologist...

Were you referred to an epilepsy center or epilepsy specialist to clarify the diagnosis or type of seizures

- Yes
- No
IF SEIZURES DON’T STOP OR IF MEDICATIONS CAUSED SIDE EFFECTS

If you continued to have bothersome side effects on one medicine, did the doctor plan to change you from one seizure medicine to another

- Yes
- No
If you have been on seizure medicines for at least two or more years, has your doctor or other health care professional recommend a test to check the health of your bones

- Yes
- No
If you have problems with mood...

If you have had symptoms or problems with your mood (for examples, problems with depression, anxiety or other changes in mood or behavior), have you been...

- Referred to a specialist in mental health
- Given a medication or other treatment for your mood
If you continued to have seizures, did anyone talk to you about...

- Compliance or how to take the medicine as prescribed
- How to take medicine more easily
- If you need to get blood levels of medicine checked and how to do this
- If the dose of seizure medicine could be changed
- If a different seizure medicine could be tried
- How to modify your lifestyle to help lessen seizures and increase safety
- When a referral to an epilepsy specialist or center may be helpful
Does anyone talk to you on a regular basis (at least once a year) about the following areas...

- How epilepsy may affect you over time
- How seizure medicines may affect you over time
- Contraception, family planning and how pregnancy and menopause may affect seizures
- Mood or behavior problems
- Factors that may trigger or affect your seizures
- Lifestyle modifications
- How epilepsy may affect other health conditions you may have
- Driving
- Safety
Depression...

Does anyone check you for signs or symptoms of depression at least once a year

- Yes
- No
If you are a woman with epilepsy of child-bearing age

Has the doctor or other health care professional discussed the following...

- The use of folic acid or folate
- Possible interactions between oral contraceptives and some seizure medicines and ways to prevent unintended pregnancy
- The type of prenatal care that is recommended during pregnancy
- The need for treatment by a neurologist and obstetrician with experience in high risk pregnancy
If you have well-controlled seizures

Has the doctor or other health care professional reviewed the following with you at least once a year...

- Side effects of seizure medicines
- How you manage epilepsy
Have you been given information on the following areas...

- Resources to learn about epilepsy
- How complex epilepsy treatment can be and the need to individualize treatment
- How to advocate for yourself in the healthcare system and with health care providers
- Possible side effects of medicine, including problems with thinking or memory, physical and sexual function
- Social services for help with jobs, Social Security Disability Insurance (SSDI), insurance, and transportation
- Local support groups or other resources for emotional support
Items for this checklist were adapted from:


- http://my.epilepsy.com/treatment/receiving_quality_care

Your Rights

• Whether you receive care as outpatient, inpatient or long-term care in a VA Medical Center or community-based outpatient clinics (CBOC), you deserve
  ▫ Timely Care
  ▫ Compassionate Care
  ▫ And the most out of your experience.
• You also have the right to a Patient Advocate
  http://www.va.gov/HEALTH/patientadvocate/
Helpful Websites & Apps

Epilepsy Foundation app available for iPhone and iPod Touch. Web version accessible at http://www.epilepsy.com/seizure diary

American Epilepsy Society app available for iPhone, iPad, Android, Blackberry Storm and Touch.
More Helpful Websites & Apps

- **Patients Like Me** offers community, information, seizure tracker, and news
  - [http://www.patientslikeme.com/](http://www.patientslikeme.com/)
- **Seizure Tracker** logs seizures, meds, appointments; interfaces with mobile phones
  - [https://www.seizuretracker.com/](https://www.seizuretracker.com/)
- **WebEase** helps you manage meds, stress, & sleep
  - [https://www.webease.org/](https://www.webease.org/)
More Helpful Websites

- Web-based tool to help identify your needs and share the information with providers.
Learn More! Epilepsy Centers of Excellence
Patient Education Video & Audio Presentations

http://www.epilepsy.va.gov/Patient_Education.asp