

Checking My Care for Epilepsy

If you or a loved one are being treated for a seizure disorder or epilepsy, use this checklist to see if you're getting some of the basic care and information that you should have. This list was made from a research study that developed 'quality indicators' for epilepsy. These indicators are a way to tell if doctors or other health care providers are providing basic quality care to people with epilepsy and seizures. This list does not include everything that people with epilepsy need, but offers a starting point for general care of their epilepsy. Please keep in mind that the word quality can be subjective and may vary from person to person. We hope this checklist will help you start looking at your epilepsy care and help you talk with your doctor.

When a person is first diagnosed with seizures or 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, if there was no obvious cause found, were you given...

- An EEG (also called an 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 (for example other neurological problems were found on an examination, an EEG showed activity that could be related to seizure activity, or a brain scan showed a structural change in the brain), or if you or your caregivers or family felt the risk of more seizures was worth trying a medicine for seizure, 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
- 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 and 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 you may take for other reasons
- First recommend that you try a medicine that does not 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

If the first treatment did not work to stop seizures or caused side effects

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

- Yes No

At follow-up appointments, did the doctor...

- Ask how often you had seizures and what kind
- Ask about side effects of medicines
- Check to see if you had side effects by examining you or checking blood tests

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 tried at least two different seizure medicines at different times that didn't work, did the doctor refer you to an epilepsy center or specialist?

- 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 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

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

For all people with 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:

[Pugh MJ, Berlowitz DR, Montouris G, et al. What constitutes high quality of care for adults with epilepsy? Neurology 2007;69:2020-2027.](#)

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

http://professionals.epilepsy.com/page/care_quality_measures.html

(http://www.ncbi.nlm.nih.gov/pubmed/17928576?ordinalpos=2&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum)