

# EPILEPSY PRE-VISIT QUESTIONNAIRE FOR RETURNING PATIENTS



**For patients and care partners completing this survey:** The intent of this survey is to gather information on how epilepsy is affecting you and/or your care partners. This information is needed to drive an effective treatment plan and ensure your safety. We understand you may not feel comfortable answering all questions via this survey, and will follow-up with you during your next visit for questions you have left blank or marked unsure about.

## Note to providers using this survey:

- This survey is made available for you to use by the American Academy of Neurology (AAN). The AAN Epilepsy Quality Measurement Set Work Group encourages you to use this pre-visit questionnaire in conjunction with the QOLIE-10-P, PHQ-2, and GAD-2. It is recommended at least 4 weeks pass between repeat questionnaire administration. The additional tools are suggested to assess behavioral health and quality of life and meet the AAN epilepsy quality measurement set 2017 update requirements.
- Survey question #7 addresses individual patient educational needs. Providers are encouraged to ensure that collection of this data is reviewed in a timely manner and concerns are addressed in a timely manner. Providers will want to review how the response is integrated into the patient's medical record to meet patient and provider needs.

## Seizure frequency

Please answer questions related to the last time you had a seizure.

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| 1a | <p>When was your last <b>Generalized Tonic Clonic (GTC) Seizure?</b></p> <p><i>In a generalized tonic clonic seizure, both sides of the body stiffen and then shake. Awareness is absent, and many people feel sore and confused afterwards. Sometimes a smaller seizure can turn into generalized tonic clonic seizure.</i></p> | <p><input type="radio"/> Never/Do not have this kind of seizure</p> <p><input type="radio"/> Today</p> <p><input type="radio"/> Up to 1 week ago</p> <p><input type="radio"/> Up to 1 month ago</p> <p><input type="radio"/> 1 to 3 months ago</p> <p><input type="radio"/> 3 to 6 months ago</p> <p><input type="radio"/> 6 to 12 months ago</p> <p><input type="radio"/> 13 to 24 months ago</p> <p><input type="radio"/> More than 2 years ago</p> <p><input type="radio"/> Unsure</p> |
| 1b | <p>If you experience Generalized Tonic Clonic seizures, how frequent are they?</p>   | <p><input type="radio"/> Multiple per day</p> <p><input type="radio"/> Daily</p> <p><input type="radio"/> Weekly but not daily</p> <p><input type="radio"/> Monthly but not weekly</p> <p><input type="radio"/> At least one per year, but not every month</p> <p><input type="radio"/> Less than once per year</p> <p><input type="radio"/> Unsure</p>   |

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| 1c | <p>When was your last <b>Motor Seizure</b> (not including generalized tonic clonic seizures)?</p> <p><i>A motor seizure is any uncontrolled movement that is caused by seizures. There are many types of motor seizures. For example, a motor seizure can be a brief twitch, a rhythmic jerking of one limb or one half of the body, a sudden fall with quick recovery, a brief stiffening of the whole body that is not followed by shaking, a drop of the head, or a sudden flailing of the arms and legs.</i></p> | <input type="radio"/> Never/Do not have this kind of seizure<br><input type="radio"/> Today<br><input type="radio"/> Up to 1 week ago<br><input type="radio"/> Up to 1 month ago<br><input type="radio"/> 1 to 3 months ago<br><input type="radio"/> 3 to 6 months ago<br><input type="radio"/> 6 to 12 months ago<br><input type="radio"/> 13 to 24 months ago<br><input type="radio"/> More than 2 years ago<br><input type="radio"/> Unsure |
| 1d | <p>If you experience Motor Seizures, how frequent are they?</p>  | <input type="radio"/> Multiple per day<br><input type="radio"/> Daily<br><input type="radio"/> Weekly but not daily<br><input type="radio"/> Monthly but not weekly<br><input type="radio"/> At least one per year, but not every month<br><input type="radio"/> Less than once per year<br><input type="radio"/> Unsure   |
| 1e | <p>When was your last <b>Nonmotor Seizure</b>?</p> <p><i>Some nonmotor seizures are called absence seizures. In an absence seizure, there is a brief lapse in awareness, often with staring, that lasts a few seconds.</i></p> <p><i>Other nonmotor seizure may last longer, and may involve changes in vision, hearing, taste, or smell. They can involve feeling nauseated or "out of it." There may be changes in breathing or heart rate.</i></p>  | <input type="radio"/> Never/Do not have this kind of seizure<br><input type="radio"/> Today<br><input type="radio"/> Up to 1 week ago<br><input type="radio"/> Up to 1 month ago<br><input type="radio"/> 1 to 3 months ago<br><input type="radio"/> 3 to 6 months ago<br><input type="radio"/> 6 to 12 months ago<br><input type="radio"/> 13 to 24 months ago<br><input type="radio"/> More than 2 years ago<br><input type="radio"/> Unsure |
| 1f | <p>If you are experiencing Nonmotor Seizures, how frequent are they?</p>   | <input type="radio"/> Multiple per day<br><input type="radio"/> Daily<br><input type="radio"/> Weekly but not daily<br><input type="radio"/> Monthly but not weekly<br><input type="radio"/> At least one per year, but not every month<br><input type="radio"/> Less than once per year<br><input type="radio"/> Unsure   |

**Please answer questions about your experiences in the last 12 months.**

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|---|---|---|
| 2 | <p>In the last 12 months, have you had a seizure lasting more than 5 minutes or back-to-back seizures?</p>                    | <input type="radio"/> Yes<br><input type="radio"/> No<br><input type="radio"/> Unsure |
| 3 | <p>In the last 12 months, have you had any emergency room visits or hospital admissions related to your seizure activity?</p> | <input type="radio"/> Yes<br><input type="radio"/> No<br><input type="radio"/> Unsure |

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|----|--|---|
| 4  | How often in the last 12 months have seizures significantly changed or impacted your usual routines (such as work or school)?  | <input type="radio"/> Every day<br><input type="radio"/> Most days (more than half)<br><input type="radio"/> Some days (less than half)<br><input type="radio"/> Once or twice<br><input type="radio"/> Never<br><input type="radio"/> Unsure   |
| 5  | How often in the last 12 months have seizure medication side effects significantly changed or impacted your usual routines (such as work or school)? Examples of common side effects include dizziness, tiredness, nausea, trouble walking, and double vision. | <input type="radio"/> Every day<br><input type="radio"/> Most days (more than half)<br><input type="radio"/> Some days (less than half)<br><input type="radio"/> Once or twice<br><input type="radio"/> Never<br><input type="radio"/> Unsure   |
| 6  | How often in the last 12 months have you missed taking your seizure medications?   | <input type="radio"/> Every day<br><input type="radio"/> Most days (more than half)<br><input type="radio"/> Some days (less than half)<br><input type="radio"/> Once or twice<br><input type="radio"/> Never<br><input type="radio"/> Unsure   |
| 6b | Have any of the following been a reason why you have missed taking your seizure medication?  | <input type="radio"/> Cost<br><input type="radio"/> Medications do not work as well as I would like them to work<br><input type="radio"/> Side effects<br><input type="radio"/> Forget to take them<br><input type="radio"/> Other  |
| 7  | What other topics do you want to learn about today?  | <input type="radio"/> None<br><input type="radio"/> SUDEP—SUDEP stands for Sudden Unexpected Death in Epilepsy and is a fatal condition associated with epilepsy<br><input type="radio"/> Rescue medications<br><input type="radio"/> New or different medications<br><input type="radio"/> Ketogenic diet<br><input type="radio"/> Neurostimulation treatments<br><input type="radio"/> Surgical treatment options<br><input type="radio"/> Patient support groups<br><input type="radio"/> Epilepsy related research opportunities<br><input type="radio"/> Other<br><input type="radio"/> Unsure |

**Please answer these questions if the person experiencing seizures is two years old or younger.**

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| 1 | When was this child's last Epileptic Spasm? An epileptic spasm usually lasts 1 to 2 seconds and may involve chin movements, grimacing or head nodding. These can occur alone or as a series of spasms, sometimes on waking from sleep. | <input type="radio"/> Never/Do not have this kind of seizure<br><input type="radio"/> Today<br><input type="radio"/> Up to 1 week ago<br><input type="radio"/> Up to 1 month ago<br><input type="radio"/> 1 to 3 months ago<br><input type="radio"/> 3 to 6 months ago<br><input type="radio"/> 6 to 12 months ago<br><input type="radio"/> 13 to 24 months ago<br><input type="radio"/> More than 2 years ago<br><input type="radio"/> Unsure |
| 2 | If this child is experiencing Epileptic Spasms, how frequent are they?   | <input type="radio"/> Multiple per day<br><input type="radio"/> Daily<br><input type="radio"/> Weekly but not Daily<br><input type="radio"/> Monthly but not Weekly<br><input type="radio"/> At least one per year, but not every month<br><input type="radio"/> Less than once per year<br><input type="radio"/> Unsure   |

**Please answer these questions if the person experiencing seizures is a female between the ages of 12 to 44 years old.**

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|---|--|---|
| 1 | Are you having periods?  | <input type="radio"/> No<br><input type="radio"/> Yes<br><input type="radio"/> I am pregnant<br><input type="radio"/> Unsure<br><input type="radio"/> I prefer not to answer  |
| 2 | Are you taking 1mg or more of folic acid in addition to your seizure medicine? | <input type="radio"/> No<br><input type="radio"/> Yes<br><input type="radio"/> Unsure<br><input type="radio"/> I prefer not to answer   |
| 3 | What contraceptive method do you use?  | <input type="radio"/> I prefer not to answer<br><input type="radio"/> None<br><input type="radio"/> Not applicable (e.g., currently pregnant)<br><input type="radio"/> Pill<br><input type="radio"/> Intrauterine Device (IUD)<br><input type="radio"/> Birth control shot<br><input type="radio"/> Condoms<br><input type="radio"/> Diaphragm<br><input type="radio"/> Subdermal implant<br><input type="radio"/> Surgical (e.g., prior tubal ligation or hysterectomy)<br><input type="radio"/> Abstinence<br><input type="radio"/> Other |