**Checklist for Providing Care to Children and Youth with Epilepsy (Initial Diagnosis)**

The purpose of this document is to provide primary care providers with the information necessary to provide care to children and youth with epilepsy, as well as to successfully transition children and youth with epilepsy to another health care provider (e.g., another pediatric primary care provider, adult primary care provider, or subspecialist).

<table>
<thead>
<tr>
<th>HISTORY:</th>
<th>TOOLS:</th>
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<tbody>
<tr>
<td>□ _____ Document seizure type(s) and frequencies (seizure diary/Seizuretracker)*</td>
<td>□ Templates (page 51+)</td>
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<tr>
<td>□ _____ Medication history (current and previous seizure treatments and side effects)</td>
<td>□ Adverse Effects Associated with Psychiatric Medications</td>
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<tr>
<td>□ _____ ER Visits and Hospitalizations, history of status epilepticus</td>
<td>□ Medications</td>
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<tr>
<td>□ _____ School Performance (ADHD, learning Challenges, 504 plan or IEP)</td>
<td>□ First unprovoked seizure (provider)</td>
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<td>□ _____ Mood / behavior of child</td>
<td>□ Treatment Guide (Families)</td>
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<td>□ _____ ADL capacity</td>
<td>□ Initial History Form</td>
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<td>□ _____ Who lives in the home?</td>
<td>○ Family History Tools</td>
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<tr>
<td>□ _____ Perinatal History (gestational age, birth weight, need for resuscitation and/or NICU; history of neonatal seizures)</td>
<td>○ 11-14</td>
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<tr>
<td>□ _____ Other medical issues</td>
<td>○ 15-21</td>
</tr>
<tr>
<td>□ _____ History of Head Trauma</td>
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<tr>
<td>□ _____ History of CNS Infections</td>
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<td>□ _____ History of febrile seizures</td>
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<tr>
<td>□ _____ Does the family have a history of epilepsy</td>
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<tr>
<td>○ _____ complete a genogram</td>
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<tr>
<td>○ _____ consider ordering genetic testing if the etiology of epilepsy is not clear—</td>
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<td>Microarray, epilepsy gene panel, or whole exome sequencing</td>
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<thead>
<tr>
<th>TESTING AND DIAGNOSIS</th>
<th>TOOLS:</th>
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<tbody>
<tr>
<td>□ Labs: Explain the necessary tests to effectively diagnosis the epilepsy/seizure disorder</td>
<td>□ Recommendations for the Assessment of Laboratory Studies (Providers)</td>
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<tr>
<td>○ MRI ___________________________ (Date)</td>
<td>□ Diagnosing the Cause of Status Epilepticus in Children (Families)</td>
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<tr>
<td>○ CT SCAN ________________________ (Date)</td>
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<td>○ EEG ____________________________ (Date)</td>
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<td>○ Blood –</td>
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<tr>
<td>▪ Ca, CMP __________________________</td>
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<tr>
<td>▪ 25 OH Vitamin D3 level ___________</td>
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<tr>
<td>▪ CBCPD</td>
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<td>▪ Other ____________________________</td>
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Genetic Testing __________________________
### Checklist for Providing Care to a Child and/or Youth with Epilepsy

#### MANAGING AND TREATING EPILEPSY
- Discuss and monitor medications to treat seizures and medication weaning
  - [Adverse Effects Associated with Psychiatric Medications (Medications)]
- Other Prescriptions:
  - Vitamin D supplementation – to maintain blood level >40 mg%
  - Folic Acid (for female teens) *
- Pros/cons of neurological surgery and interventions*
- Equipment:
  - Mobility
  - Incontinence management
  - Safety
- Special diet recommendations
- Discuss SUDEP, when appropriate
- Discuss driving laws

#### TOOLS:
- First unprovoked seizure (provider)
- Treatment Guide (Families)
- Refer to [local Epilepsy Foundation](#) for assistance
- Refer to [Child Neurology Foundation](#) for assistance
- Refer to [Healthy Children.org](#)

#### TRANSITIONS AND CARE COORDINATION
- Pediatrician to adult provider (when/how)
- Emergency/Hospital Setting
- ER Discharge / Hospital discharge
- Specialist (Neurologist, etc.)

#### TOOLS:
- Co-Management Agreement
- Why Is It Important for Primary Care Providers to Help Families Prepare to Transition from Pediatric to Adult Care? (video)
- How Does a Medical Home Support Transitioning from Pediatric to Adult Care? (Video)
- Gottransitions.org
- Pediatric Care Coordination Curriculum
- Comprehensive Care Planning

#### COUNSELING PATIENT AND FAMILY
- Describe etiology of epilepsy
- Discuss what to do in the event of a seizure, what to do in public
- Create a Seizure Action Plan. Update it at every visit.
- Give Seizure Action plan to CYE and family
- Bathing/water safety- Explain the dangers bathing and water*
- What to do in an emergency and working with Emergency Room Provider
- Co-morbidities (learning, behavioral, educational)
- Prognosis/Outcomes
- SUDEP
- Standardized referral for support services
- If the child is in sports, discuss precautions (helmets)*
- If the child is able to drive or learning to drive, review [State Law Database*]
- Sharing the Diagnosis with family members, friends, school (managing medications when your child is away)

#### TOOLS:
- Seizure Observation and Recording:
- Seizure Description Form
- Childhood Seizure Reporting Form
- First Aid
- Emergency Information Form for Children with Special Healthcare Needs
- Preparticipation Sports Forms (includes a history form to share information about seizures, medications, clearance form, and more)
- Staying Safe
- Lesson plans on teaching students about epilepsy
- Seizure Action Plan for School
- Childcare Providers and Babysitters
- Epilepsy at School: Guidelines for School Personnel
- School Nurse Poster
- Epilepsy Handbook for School Nurses
- Preparing for Camp
- Classroom Resources
Checklist for Providing Care to a Child and/or Youth with Epilepsy

**TIPS ON WHEN TO COVER TOPICS (INITIAL/ONGOING):**

**Initial diagnosis:**
- Describe etiology of epilepsy, including prognosis and outcomes
- Co-morbidities (learning, behavioral, educational)
- Create/Update/Share a Seizure Action Plan
  - Discuss what to do in the event of a seizure
  - Discuss what to do in the case of an emergency and working with the emergency providers
  - Assure that it is a “portable” document
- Standardized referral for support services
- Sharing the diagnosis with family members, friends, school (managing medications when your child is away)

**Each Encounter/As Necessary per Age/Patient Needs:**
- Integrate elements of medical home from the survey
  - Sample questions: How long does a bottle of medicine last? (to determine medication adherence) Who lives in your home? Where else does your child go in a month?
- Review, update, and share the Seizure Action Plan
  - Discuss what to do in the event of a seizure
  - Discuss what to do in the case of an emergency and working with emergency providers
- Safety issues:
  - Sports
  - Bathing - Bathing/water safety (explain the dangers and precautions)*
  - Driving - If the child is able to drive or learning to drive, review driving and state driving laws*
  - Precautions (helmets)*
    - Sample Questions: What color is your helmet? (to ensure that the child has a helmet)
- Interim Hospital/ER visits
  - Discuss potential adverse childhood experiences
    - Sample Questions: Does the patient experience any learning, social, or emotional challenges? Does your child have a best friend? Does your child talk with anyone during recess time at school? (to ensure social interaction)
  - Discuss Sudden Unexplained Death in Epilepsy, where indicated
  - Discuss sexual/reproductive health and where appropriate teratogenicity of anti-seizure medications
# Checklist for Providing Care to a Child and/or Youth with Epilepsy

## Checklist of American Academy of Neurology Quality Metrics

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<tr>
<th>Discussed</th>
<th>N/A</th>
<th>Measure</th>
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|           |     | Seizure type and current seizure activity.  
All visits with the type(s) of seizures and current seizure frequency for each seizure documented in the medical record. |
|           |     | Documentation of etiology of epilepsy or epilepsy syndrome  
All visits with the etiology of epilepsy or epilepsy syndrome reviewed and documented if known, or documented as unknown. |
|           |     | EEG results reviewed, requested, or test ordered  
All initial evaluations with the results of at least one EEG reviewed or requested, or if EEG was not performed previously, then an EEG ordered. |
|           |     | MRI/CT scan reviewed, requested, or scan ordered.  
All initial evaluations with the results of at least one MRI or CT scan reviewed or requested or, if a MRI or CT scan was not obtained previously, then a MRI or CT scan ordered (MRI preferred). |
|           |     | Querying and counseling about antiepileptic drug side effects  
All visits where patients were queried and counseled about antiepileptic drug side effects and the querying and counseling was documented in the medical record. |
|           |     | Surgical therapy referral consideration for intractable epilepsy  
All patients with a diagnosis of intractable epilepsy are considered for referral for a neurological evaluation of appropriateness for surgical therapy and the consideration was documented in the medical record within the past 3 years. |
|           |     | Counseling about epilepsy safety issues  
All patients who were counseled about context-specific safety issues, appropriate to the patient’s age, seizure type(s) and frequency(ies), occupation, and leisure activities, etc. (e.g. injury prevention, burns, appropriate driving restrictions, or bathing) at least once per year. |
|           |     | Counseling for women of childbearing potential with epilepsy  
All female patients of childbearing potential (12-44 years old) diagnosed with epilepsy who were counseled about epilepsy and how its treatment may affect contraception and pregnancy at least once per year. |