

Checklist for Providing Care to a Child and/or Youth with Epilepsy

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).

<p>HISTORY:</p> <ul style="list-style-type: none"> <input type="checkbox"/> _____ Document seizure type(s) and frequencies (seizure diary/Seizuretracker*) <input type="checkbox"/> _____ Medication history (current and previous seizure treatments and side effects) <input type="checkbox"/> _____ ER Visits and Hospitalizations, history of status epilepticus <input type="checkbox"/> _____ School Performance (ADHD, learning Challenges, 504 plan or IEP) <input type="checkbox"/> _____ Mood / behavior of child <input type="checkbox"/> _____ ADL capacity <input type="checkbox"/> _____ Who lives in the home? <input type="checkbox"/> _____ Perinatal History (gestational age, birth weight, need for resuscitation and/or NICU; history of neonatal seizures) <input type="checkbox"/> _____ Other medical issues <input type="checkbox"/> _____ History of Head Trauma <input type="checkbox"/> _____ History of CNS Infections <input type="checkbox"/> _____ History of febrile seizures <input type="checkbox"/> _____ Does the family have a history of epilepsy <ul style="list-style-type: none"> <input type="checkbox"/> _____ complete a genogram <input type="checkbox"/> _____ consider ordering genetic testing if the etiology of epilepsy is not clear—Microarray, epilepsy gene panel, or whole exome sequencing 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Templates (page 51+) <input type="checkbox"/> Adverse Effects Associated with Psychiatric Medications <input type="checkbox"/> Medications <input type="checkbox"/> First unprovoked seizure (provider) <input type="checkbox"/> Treatment Guide (Families) <input type="checkbox"/> Initial History Form <ul style="list-style-type: none"> <input type="checkbox"/> Family History Tools <input type="checkbox"/> 11-14 <input type="checkbox"/> 15-21
<p>TESTING AND DIAGNOSIS</p> <ul style="list-style-type: none"> <input type="checkbox"/> Labs: Explain the necessary tests to effectively diagnosis the epilepsy/seizure disorder <ul style="list-style-type: none"> <input type="checkbox"/> MRI _____ (Date) <input type="checkbox"/> CT SCAN _____ (Date) <input type="checkbox"/> EEG _____ (Date) <input type="checkbox"/> Blood – <ul style="list-style-type: none"> <input type="checkbox"/> Ca, CMP _____ <input type="checkbox"/> 25 OH Vitamin D3 level _____ <input type="checkbox"/> CBCPD _____ <input type="checkbox"/> Other _____ Genetic Testing _____ 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Recommendations for the Assessment of Laboratory Studies (Providers) <input type="checkbox"/> Diagnosing the Cause of Status Epilepticus in Children (Families)

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<p>MANAGING AND TREATING EPILEPSY</p> <ul style="list-style-type: none"> <input type="checkbox"/> _____ Discuss and monitor medications to treat seizures and medication weaning (Adverse Effects Associated with Psychiatric Medications) <ul style="list-style-type: none"> ▪ Medications <input type="checkbox"/> _____ Other Prescriptions: <ul style="list-style-type: none"> ○ _____ Vitamin D supplementation – to maintain blood level >40 mg% ○ _____ Folic Acid (for female teens) * <input type="checkbox"/> _____ Pros/cons of neurological surgery and interventions* <input type="checkbox"/> _____ Equipment: <ul style="list-style-type: none"> ○ _____ Mobility ○ _____ Incontinence management ○ _____ Safety <input type="checkbox"/> _____ Special diet recommendations <input type="checkbox"/> _____ Discuss SUDEP, when appropriate <input type="checkbox"/> _____ Discuss driving laws 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> First unprovoked seizure (provider) <input type="checkbox"/> Treatment Guide (Families) <input type="checkbox"/> Refer to local Epilepsy Foundation for assistance <input type="checkbox"/> Refer to Child Neurology Foundation for assistance <input type="checkbox"/> Refer to Healthy Children.org
<p>TRANSITIONS AND CARE COORDINATION</p> <ul style="list-style-type: none"> <input type="checkbox"/> _____ Pediatrician to adult provider (when/how) <input type="checkbox"/> _____ Emergency/Hospital Setting <input type="checkbox"/> _____ ER Discharge / Hospital discharge <input type="checkbox"/> _____ Specialist (Neurologist, etc.) 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Co-Management Agreement <input type="checkbox"/> Why Is It Important for Primary Care Providers to Help Families Prepare to Transition from Pediatric to Adult Care? (video) <input type="checkbox"/> How Does a Medical Home Support Transitioning from Pediatric to Adult Care? (Video) <input type="checkbox"/> Gottransitions.org <input type="checkbox"/> Pediatric Care Coordination Curriculum <input type="checkbox"/> Comprehensive Care Planning
<p>COUNSELING PATIENT AND FAMILY</p> <ul style="list-style-type: none"> <input type="checkbox"/> _____ Describe etiology of epilepsy <input type="checkbox"/> _____ Discuss what to do in the event of a seizure, what to do in public <input type="checkbox"/> _____ Create a Seizure Action Plan. Update it at every visit. <input type="checkbox"/> _____ Give Seizure Action plan to CYE and family <input type="checkbox"/> _____ Bathing/water safety- Explain the dangers bathing and water* <input type="checkbox"/> _____ What to do in an emergency and working with Emergency Room Provider <input type="checkbox"/> _____ Co-morbidities (learning, behavioral, educational) <input type="checkbox"/> _____ Prognosis/Outcomes <input type="checkbox"/> _____ SUDEP <input type="checkbox"/> _____ Standardized referral for support services <input type="checkbox"/> _____ If the child is in sports, discuss precautions (helmets)* <input type="checkbox"/> _____ If the child is able to drive or learning to drive, review State Law Database* <input type="checkbox"/> _____ Sharing the Diagnosis with family members, friends, school (managing medications when your child is away) 	<p>TOOLS:</p> <ul style="list-style-type: none"> <input type="checkbox"/> Seizure Observation and Recording; <input type="checkbox"/> Seizure Description Form <input type="checkbox"/> Childhood Seizure Reporting Form <input type="checkbox"/> First Aid <input type="checkbox"/> Emergency Information Form for Children with Special Healthcare Needs <input type="checkbox"/> Preparticipation Sports Forms (includes a history form to share information about seizures, medications, clearance form, and more) <input type="checkbox"/> Staying Safe <input type="checkbox"/> Lesson plans on teaching students about epilepsy <input type="checkbox"/> Seizure Action Plan for School <input type="checkbox"/> Childcare Providers and Babysitters <input type="checkbox"/> Epilepsy at School: Guidelines for School Personnel <input type="checkbox"/> School Nurse Poster <input type="checkbox"/> Epilepsy Handbook for School Nurses <input type="checkbox"/> Preparing for Camp <input type="checkbox"/> Classroom Resources

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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

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CHECKLIST OF AMERICAN ACADEMY OF NEUROLOGY QUALITY METRICS

Discussed	N/A	Measure
<input type="checkbox"/>	<input type="checkbox"/>	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.
<input type="checkbox"/>	<input type="checkbox"/>	Documentation of etiology of epilepsy or epilepsy syndrome All visits with the etiology or epilepsy or epilepsy syndrome reviewed and documented if known, or documented as unknown.
<input type="checkbox"/>	<input type="checkbox"/>	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.
<input type="checkbox"/>	<input type="checkbox"/>	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).
<input type="checkbox"/>	<input type="checkbox"/>	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.
<input type="checkbox"/>	<input type="checkbox"/>	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.
<input type="checkbox"/>	<input type="checkbox"/>	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.
<input type="checkbox"/>	<input type="checkbox"/>	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.