

Guidelines for the Care of Children and Adolescents with a Seizure Disorder

Basic Team

The special care needs of children with a seizure disorder can be met by an experienced primary care physician working collaboratively with parents, a pediatric neurologist, and school staff. Some children and families require referral to an experienced neurodevelopmental or child development team headed by a developmental pediatrician, and other children may need referral to a mental health professional. Please note that the primary care physician continues to be responsible for coordinating the special services that these children require.

Initial Evaluation

The objectives of the initial evaluation are to document the seizure type or the presence of an epilepsy syndrome, identify associated medical and developmental problems, and clarify the cause of the seizures if possible. The responsibilities of the primary care physician and nurse are to complete parent and child interviews, perform a complete medical and laboratory evaluation, initiate treatment, determine the need for referrals, and counsel the parents and child about the diagnosis and recommended treatment.

Frequency of Visits

The child and family should be followed at least monthly by the primary care office following the initiation of the antiepilepsy drug treatment until the child's seizures are being controlled well, the medical evaluation is complete, and the child is receiving recommended services. The child and the family are reevaluated best in the office twice yearly if the child is stable and doing well with the treatment program, and more frequently for younger children and in the first year of treatment. In addition, the physician and office staff may need to have frequent telephone interviews with parents and/or teachers and obtain behavior rating scales as needed. Many children need ongoing management by the pediatric neurologist. The office management plan should be updated as needed at each reevaluation and not less than yearly.

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The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–5 years (pre-school age)	<p><i>Growth/Nutrition</i> (if associated developmental disability)</p> <p>Oral motor dysfunction</p> <p>Failure to thrive (FTT)</p> <p>Intrauterine growth retardation (IUGR)</p> <p>Microcephaly or macrocephaly</p>	<p>Growth parameters, diet history</p> <p>Cranial magnetic resonance imaging (MRI) or computed tomography (CT) scan</p>	<p>Nutritionist or feeding specialist as needed</p>
	<i>Dental Care</i>	Review oral hygiene	Dentist
	<i>Associated Medical Problems</i>		Audiologist, ophthalmologist as needed
	Hearing and vision problems	Hearing and vision testing as needed	Developmental pediatrician (DPed), physical therapist or neurodevelopmental team as needed
	Neuromotor concerns (e.g., cerebral palsy, ataxia)	Detailed musculoskeletal and neuromotor examinations	
	Constipation	Diet, medication (e.g., bulk agent), gastrointestinal referral as needed	
	Enuresis	Urinalysis culture as needed, behavioral or other management, urology referral as needed	
	Sleep disorder	Behavioral management and occasionally medication	
	Note any side effects of medications.		
	<i>Cause of Seizures</i>		Pediatric neurologist, DPed, medical geneticist, metabolic specialist as needed
	Epilepsy syndrome present?	Evaluation for minor anomalies, careful skin/physical examination	
	Possible degenerative disorder?	Electroencephalogram (EEG), MRI or CT scan, blood chromosomes, other laboratory studies	
	<i>Management of Seizures</i>		Pediatric neurologist, dietitian as needed
	Follow-up of antiepilepsy drugs (AEDs)	Behavioral rating scales and teacher report as needed	Collaborate with school staff
	Ketogenic diet	Check growth, blood pressure, and heart rate; side effects as needed and at least twice yearly if stable and doing well	
	Other (e.g., adrenocorticotropic hormone [ACTH])	EEG, blood AED level, other lab work as needed for specific seizure types or medications	

Guidelines for the Care of Children and Adolescents with a Seizure Disorder *(continued)*

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AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
Birth–5 years (pre–school age) <i>(continued)</i>	<p><i>Associated Behavior/Mental Health Problems</i></p> <p>Inattention or hyperactivity</p> <p>Aggression</p> <p>Oppositional behaviors</p> <p>Anxiety</p> <p>Lethargy</p>	<p>Family interview, behavior rating scales, school information as needed</p> <p>Parent training in behavior management as needed</p> <p>Referral to mental health professional as needed</p>	<p>DPed, behavioral specialist, mental health professional as needed</p>
	<p><i>Developmental Progress, Need for Early Intervention/Early Childhood Special Education (EI/ECSE) Services</i></p> <p>Language delay/speech disorder</p> <p>Developmental delay</p>	<p>Developmental screening and surveillance</p> <p>Referral for eligibility testing for EI/ECSE services as needed</p>	<p>Psychologist, speech-language pathologist, child development team as needed</p>
	<p><i>Family Support Services</i></p> <p>Respite care</p> <p>Parent group</p> <p>Community health nurse</p> <p>Advocacy</p> <p>Financial support (e.g., Supplemental Security Income [SSI])</p>	<p>Family interview, use parent questionnaire (e.g., Family Needs Survey), provide resource materials, referral to community services as needed</p>	<p>Medical social worker, referral to community health nurse as needed</p>
	<p><i>Review of Diagnosis and Anticipatory Guidance</i></p> <p>Review of seizure recognition</p> <p>Review first aid for seizure</p> <p>Warn against sudden discontinuation of AEDs</p> <p>Communication with school (e.g., type of seizures, medications, possible side effects)</p> <p>Advice regarding accident prevention and protection (e.g., need for helmet)</p> <p>Review individualized family service plan (IFSP) with family</p> <p>Transition to ECSE grade school</p>	<p>Family interview, educational materials, initiate care notebook</p> <p>Review IFSP with family; hold teacher interview, school conference as needed</p>	<p>Primary care office in collaboration with specialists</p>
	<p><i>Collaboration with Community Services</i></p> <p>Community health nurse</p> <p>Educational services</p>	<p>Comprehensive care coordination with regular exchange of written information (at least yearly) with other service providers</p>	<p>Primary care office in collaboration with specialists</p>

Guidelines for the Care of Children and Adolescents with a Seizure Disorder (continued)

The following elements are recommended by age group, and the listing is cumulative. Review all items indicated up through the actual age group of a child entering your practice for the first time as part of the initial evaluation.

AGE	KEY CLINICAL ISSUES/CONCERNS	EVALUATIONS/KEY PROCEDURES	SPECIALISTS
6–12 years (school age)	<p><i>Management of Seizures</i></p> <ul style="list-style-type: none"> Review indications for discontinuation of AEDs (if child is currently seizure-free) Review indications for epilepsy surgery (if child has had uncontrolled seizures) <p><i>School Progress</i></p> <ul style="list-style-type: none"> Learning disabilities Mental retardation <p><i>Associated Behavior/Mental Health Problems</i></p> <ul style="list-style-type: none"> Attention-deficit/hyperactivity disorder (ADHD) Oppositional behaviors Aggression Anxiety, depression Schizophrenia, psychotic disorder 	<ul style="list-style-type: none"> Continue to monitor for side effects of AEDs, blood AED levels and laboratory tests as indicated Repeat EEG as needed, referral to epilepsy center <p>Intellectual and achievement testing as needed</p> <p>Child and parent interviews, behavioral rating scales, school report, teacher interview as needed</p> <p>Review medication management</p>	<ul style="list-style-type: none"> Pediatric neurologist, epilepsy center as needed Collaborate with school staff <p>Psychologist or referral to child development team as needed</p> <p>DPed, child psychiatrist, mental health professional as needed; collaborate with school staff</p>
13–21 years (adolescent–young adult)	<p><i>Social Skills</i></p> <ul style="list-style-type: none"> Promote social competence Involvement in peer group activities at school and in the community (determine which supports are needed) <p><i>Anticipatory Guidance</i></p> <ul style="list-style-type: none"> Transition to high school Encourage healthy behaviors (e.g., diet, exercise) High-risk behaviors (e.g., substance use or abuse, promiscuity) Career planning Transition to adult services and independent living 	<p>School-based program; encourage participation in community programs</p> <p>Adolescent, family interviews</p> <p>Teacher interview, school conference as needed</p> <p>Referral to mental health professional as needed</p> <p>Referral to Department of Vocational Rehabilitation, career counseling, or life skills program as needed</p>	<p>Psychologist, adaptive physical education specialist as needed</p> <p>Collaborate with school staff</p> <p>Primary care office in collaboration with specialists and school staff</p>

Family and Physician Management Plan Summary for Children and Adolescents with a Seizure Disorder

The Management Plan Summary should be completed at each annual review and more often as needed. It is intended to be used with the Guidelines for Care, which provide a more complete listing of clinical issues at different ages as well as recommended evaluations and treatments.

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Family's Questions</i>					
<i>Growth and Nutrition</i>					
<i>Dental Care</i>					
<i>Other Medical Problems</i> Hearing loss or vision concerns Neuromotor problems Constipation, enuresis Sleep disorder Note any side effects of medications.					

Family and Physician Management Plan Summary for Children and Adolescents with a Seizure Disorder *(continued)*

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<p><i>Associated Developmental/Learning Issues</i></p> <p>Describe current school achievement</p> <p>Review early intervention (EI) or other school services (individualized family service plan [IFSP] or individualized education program [IEP])</p> <p>Learning disability</p> <p>Speech-language disorder</p> <p>Developmental delay or mental retardation</p>					
<p><i>Associated Behavior/Mental Health Problems</i></p> <p>Inattention or hyperactivity</p> <p>Aggression</p> <p>Oppositional behavior</p> <p>Anxiety, depression</p> <p>Schizophrenia (psychotic disorder)</p> <p>High-risk behaviors</p>					
<p><i>Social Skills</i></p> <p>Involvement in peer-group activities at school and in the community (determine which supports are needed)</p>					

Family and Physician Management Plan Summary for Children and Adolescents with a Seizure Disorder (continued)

Child's name _____ Person completing form _____ Today's date _____

Clinical issues	Currently a problem?	Evaluations needed	Treatment recommendations	Referrals made	Date for status check
<i>Self-Care and Independence</i>					
<i>Family Support Services</i>					
<i>Anticipatory Guidance</i> List issues discussed and materials provided					
<i>Collaboration with Community Agencies</i> Communication with school					
Comments					

Next update of the Management Plan Summary _____

Signature _____ Date _____
(Child and parent)

Signature _____ Date _____
(Health professional)

