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KITSAP COUNTY CHILD HEALTH NOTES

Promoting early identification and partnerships between families, primary health care providers & the community.

Distributed by: (2)

Contributors: Washington State Department of Health and UW – Center on Human Development & Disability

CARE COORDINATION FOR CHILDREN & YOUTH WITH EPILEPSY

Epilepsy is a chronic neurological condition characterized by two or more seizures.

- The term “epilepsy” can be used interchangeably with “seizure disorder”
- Manifestations of a seizure are varied and may range from staring, lip smacking, eye deviation or generalized tonic clonic.

Epilepsy is the most common neurological condition in children and impacts 6,100 -15,000 children in Washington State. Functional performance in school, home, daily self-care, and community participation can be significantly impaired. Children and youth with epilepsy are often socially stigmatized and there is a high incidence of depression.

Diagnosis and Evaluation: Role of the Primary Care Provider

- Obtain a detailed description of the suspected seizure activity and events preceding and following the event; if the events occur frequently, a video tape recording of the activity may be helpful. Note: staring spells may be distinguished from daydreaming by the lack of response to physical manipulation during the event.
- Determine if the seizure(s) is due to an acute neurological condition that requires emergency treatment.
- Obtain information from school teachers and/or childcare providers regarding recent changes in behavior, developmental performance, or academic performance
- Perform a full developmental screening test to help identify any possible developmental delays
- Perform a comprehensive physical examination
- Obtain and review results from EEG testing, laboratory evaluations, or other diagnostic measures
- If a referral is needed, gather all this information together and send it to the consulting Neurologist in advance of the clinic appointment. Providing parents with copies of these reports is also helpful.

Consider using these tools:

Pediatric Neurology Consult and Referral Guidelines

<https://www.seattlechildrens.org/clinics/neurosciences/services/epilepsy-program/>

Care Coordination Tools for Providers and Families

<https://www.childneurologyfoundation.org/tools-resources/>

- Guidelines for Care of children and Adolescents with Seizure Disorder
- Seizure Action Plan (*English & Spanish*)
- Seizure Medication List (*English & Spanish*)

For Consultation with a Pediatric Neurologist:

Community primary care providers within the WWAMI region may consult by telephone with a pediatric neurologist through primary health care providers within the School of Medicine Faculty at the University of Washington

800-489-3627 or <https://www.uwmedicine.org/practitioner-resources>

Referral Sources: For Child to See a Neurologist

- Seattle Children’s Hospital & Regional Medical Center Neuroscience.....206-987-2016
- Mary Bridge Pediatric Neurology.....253-792-6630

Care Management Tools for Office Practice Co-management is an optimal strategy for managing care for children with epilepsy and their families. Co-management is coordinated communication between the child and family primary health care provider, neurologist, medical specialists, and others participating in the child's care. Provider tools and parent materials are available online to support co-management for children with epilepsy.

Care Coordination Tools:

A written care plan may be developed in partnership with the primary care provider and family for the purpose of providing important information to those who care for the child. This may include information about medications, what to do in case of emergency, contact information for care team members, etc... Here are examples of ready-to-use formats.

Care Plans..... <https://nurseslabs.com/4-seizure-disorder-nursing-care-plans/>

CYSCHN Coordinators..... <https://3.basecamp.com/4005047/projects/29698765>

Parent Materials:

Family Care Coordination Notebook/Organizer..... (English & Spanish)

(a system for families to organize and manage important health documents)

Epilepsy & Seizure Disorder: Resource Guide for Parents (2007); USC UCEED & Children's Hospital Los Angeles

www.epilepsyfoundation.org/local/norcal/Parents-Resource-Guide.cfm

Seizures/Epilepsy: Answers to Common Questions... <https://www.seattlechildrens.org/conditions/epilepsy/>

Safety Tips for Children with Seizure <https://www.healthychildren.org/english/health-issues/conditions/seizures/pages/seizures-and-epilepsy-in-children.aspx>? (English & Spanish)

Water Safety for Children with Epilepsy..... <https://www.epilepsy.com/stories/water-safety-and-seizures>

Seizures First Aid. ... <https://www.epilepsy.com/parents-and-caregivers/talking-kids-about-epilepsy/first-aid>
(English & Spanish)

Abstract Information on the Vagal Nerve Stimulator

Of the 3 million patients with seizures in North America approximately 70% have effective seizure control with medications. In the group refractory to medical treatment only a minority fit the criteria for surgical therapy. Vagus nerve stimulation therapy seems to be a suitable nonpharmacologic therapy for reducing seizure frequency in these cases. It is a simple device with 2 electrodes and an anchor loop implanted on the midcervical portion of left vagus nerve and the impulse generator is implanted subcutaneously in the left infraclavicular region. The left vagus is the preferred site as the right vagus innervates the sinoatrial node and influences the heart rate. Data from laboratory studies suggest that it most probably works by increasing the release of norepinephrine in the locus ceruleus, which in turn increases the seizure threshold. More than 32,000 devices have been implanted since it was approved in 1997. There is class I evidence that vagus nerve stimulator reduces the frequency of seizures. In addition it also elevates the patients' mood-independent of seizure control. In one of the studies 50% reduction in seizure frequency was 37% in the first year and 44% in the second and third year. The side effects commonly reported are constriction in the throat, change in voice, and throat pain which most patients are able to tolerate and continue the use of the device. In conclusion VNS seems to be an effective nonpharmacologic therapy for medically refractory partial onset seizures.

EPILEPSY LINKS:

- **Regional:** Epilepsy Foundation Northwest www.epilepsynw.org
- **National:** Epilepsy Foundation www.epilepsyfoundation.org
American Epilepsy Society www.aesnet.org
National Institute for Neurological Disorders & Stroke www.ninds.nih.gov

