



Empowering Children. Supporting Families. Building Brighter Futures.

Resource 059 | Brain, spinal cord, and seizure conditions

Developmental and epileptic encephalopathies

What it means

Developmental and epileptic encephalopathies (DEEs) are a group of conditions in which an underlying disorder and epileptic activity both contribute to developmental difficulties. They are not one diagnosis with one treatment. Individual abilities, seizure patterns, and outcomes differ substantially across syndromes and children. [1]

Causes and risk factors

Genetic changes, structural brain differences, injury, and metabolic conditions can cause DEEs. Some causes remain unidentified. Developmental difficulties may start before seizures or emerge later. The relative contribution of the underlying condition and epilepsy varies; a child's course cannot be predicted from this umbrella term alone. [1,2]

General family education. A concern deserves assessment, but this guide does not diagnose a child or prescribe treatment.



Signs and everyday impact

Signs may include seizures that are difficult to control, developmental delay or regression, movement differences, and challenges with sleep, feeding, or communication. Some children have frequent subtle events rather than convulsions. A change in alertness or participation may reflect seizures, illness, or medicine effects and needs assessment. [1,2]

Assessment and diagnosis

Pediatric neurology reviews seizure history, development, examination, and EEG findings. MRI and selected genetic or metabolic investigations help clarify cause and syndrome. Repeated developmental assessment identifies support needs. Reports should name the specific diagnosis when possible rather than stopping at the broad DEE label. [1,2]

Treatment and therapy

Care combines syndrome-appropriate seizure treatment with support for the underlying condition. Selected children may benefit from a specialist dietary treatment, surgery, or targeted therapy when available and indicated. Physical, occupational, and speech-language therapy, AAC, nutritional care, and educational accommodations support participation. A coordinated team monitors health, comfort, medicine effects, and family priorities. [1,2,3,4]

Support at home

Agree on a written seizure plan and a way to distinguish usual events from changes requiring help. Use communication options that match the child's motor and sensory abilities. Keep meaningful goals small and practical, such as making choices or joining play. Review equipment, sleep, feeding, and caregiver support as needs change.

When to seek help

Use the seizure emergency plan for prolonged events or repeated seizures without recovery. Seek urgent assessment for breathing problems, marked reduction in alertness, new loss of skills, or inability to maintain hydration.

Questions for your care team

- What specific syndrome or cause has been identified?
- Could targeted treatment or further testing change care?
- Which functional goals and health checks should our team prioritize?



Podcast preparation

Use this outline to develop a later podcast script.

Suggested opening

Welcome to Mariel Early Intervention. Today we discuss developmental and epileptic encephalopathies. Developmental and epileptic encephalopathies (DEEs) are a group of conditions in which an underlying disorder and epileptic activity both contribute to developmental difficulties. This is general education; each child needs individualized care.

Opening: Define the topic and its developmental context.

Understanding: Explain causes and signs without inviting self-diagnosis.

Assessment: Describe evaluation and distinguish screening from diagnosis.

Support: Discuss treatment, therapy, and practical family supports.

Closing: Explain urgent signs and one clear next step.

Misconception to address: Myth: the DEE label predicts a single outcome. The specific cause and each child's course matter.

Before recording: update clinical references and local service details, arrange clinical review, and use fully consented or fictional examples.

Terms in plain language

- Encephalopathy: a broad term for impaired brain function.
- Syndrome: a recognizable pattern of features.
- AAC: communication methods that support or supplement speech.

Sources and further reading

Sources accessed 3 October 2026. Numbered references support the clinical overview. Treatment availability and referral routes vary by country.

[1] Epilepsy and Seizures

<https://www.ninds.nih.gov/node/647>

[2] INFANTILE EPILEPTIC SPASMS SYNDROME (IESS)

<https://www.epilepsydiagnosis.org/syndrome/west-syndrome-overview>

[3] 6 Treating childhood-onset epilepsies

<https://www.nice.org.uk/guidance/ng217/chapter/treating-childhood-onset-epilepsies>

[4] First Aid for Seizures

<https://www.cdc.gov/epilepsy/first-aid-for-seizures/index.html>