What is DEE?

(Developmental and Epileptic Encephalopathy)

Different Diagnoses. Shared Challenges.

DEE is a medical term used to describe a **group of rare epilepsy conditions** that share certain challenges, like early onset, treatment-resistant seizures, effects on development, and a significant impact on daily life for those affected and their caregivers.

D DEVELOPMENTAL

Refers to challenges with learning, growth, or development that may begin early in life and continue over time

E EPILEPTIC

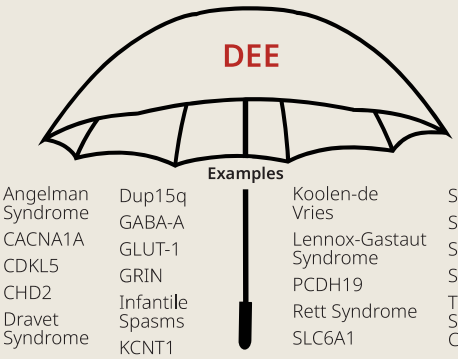
Refers to seizures that occur as a part of the condition

E ENCEPHALOPATHY

Refers to the effects of any disorder on the structure or function of the brain

Many Diagnoses May Qualify as DEE

Some DEE syndromes are closely linked to a specific genetic, structural, or metabolic cause. Others may have multiple possible causes—or no clear cause at all.



This list is **NOT exhaustive.** There are **hundreds of causes for DEE**, with new ones continuing to be identified.

Signs & Symptoms

- **Frequent seizures** of different types that are resistant to 2 or more anti-seizure medications (ASMs) **AND** a **delay or loss of developmental skills**
- Changes in **learning, movement, behavior, or sleep**
- **Feeding or communication challenges**
- Other medical issues may also occur

Why All Diagnoses Matter

Adding a DEE diagnosis does not change your individual syndrome or genetic diagnosis, but may help to:

- Understand **shared challenges**
- Inform your **treatment plan**
- Access **research, specialists, wraparound services, and social support**

What You Can Do

- Talk with **your or your loved one's doctor** about your concerns
- Request an evaluation by an **epilepsy specialist or neurologist**
- Keep **notes and videos** of seizure events to share with your provider

Diagnosing DEE

Only a clinician can diagnose DEE. Common steps include:

History & Exam
including seizure pattern, development, regression/loss of skills

Electroencephalogram (EEG)
to assess brain-wave patterns

Imaging
eg, brain MRI, to look for structural changes

Genetic Testing
to look for underlying causes

Team Review
eg, neurologists, epileptologists, neuropsychologists, and geneticists/genetic counselors

Talk with your healthcare provider about whether a DEE diagnosis may be relevant to your or your loved one's care plan.

This educational document is intended for US distribution only and is not a substitute for medical advice. Always talk to your healthcare provider—your best resource for medical information.

References: Child Neurology Foundation. www.childneurologyfoundation.org. Accessed March 10, 2026. Dup15q Alliance. www.dup15q.org. Accessed August 20, 2026. Freibauer AE, et al. *Seizure*. 2023;110:119-125. Scheffer IE, et al. *Nat Rev Dis Primers*. 2024;10(1):61.

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