

Understanding DEEs: More Than Just Seizures

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DEEs Affect the Whole Child

Seizures are only one part. DEEs affect how a child thinks, moves, and feels.

Beyond seizures, children often face challenges with **sleep, digestion, and behavior.**

These "other challenges" often impact daily life just as much as the seizures themselves.

Every child is unique, and their needs will naturally change as they grow.



Learning



Sleep



Digestion



Mood

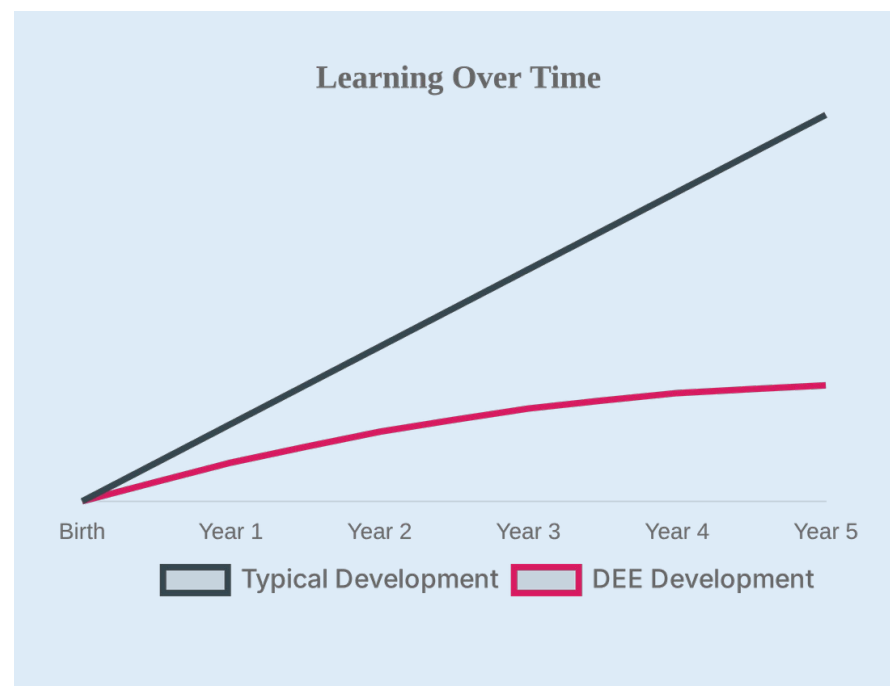
The "Widening Gap" in Learning

Progress continues. Most children keep gaining new skills and reaching milestones over time.

However, the **gap** between them and peers often grows wider as they get older.

This is "**developmental slowing**" - they are still moving forward, just at their own pace!

Early support and therapies are the best ways to help every child reach their full potential.



Strength, Balance, and Everyday Motion

Exploring the world. Many children face challenges with balance, walking, or using their hands.

Muscle changes. Some children may have "extra" movements or muscles that feel very stiff.

Essential tools. Physical and occupational therapies help children stay active and comfortable.

Sources: Mastrangelo 2025; van der Veen 2023; Kollia 2025



Sitting & Standing



Walking Support



Daily Skills



Staying Active

Understanding Behavior as Communication

Behavior is communication. It is common for children to feel frustration, anxiety, or high energy.

Medication impact. Sometimes, seizure medicines can affect a child's mood or personality.

Check with doctors. Identifying if a behavior is a side effect can help with adjustments.

Supportive home. Understanding these feelings helps us stay patient and supportive.



Happy



Frustrated



Tired



High Energy

SUDEP and Mortality — A Difficult but Important Topic

An important risk to know about. SUDEP is responsible for roughly half of all deaths among people with genetic DEEs.

Some children carry higher risk. SUDEP risk is greatest in SCN1A-related DEEs, including Dravet syndrome.

There are ways to help protect your child. Nocturnal supervision is associated with a reduced risk of SUDEP.

You don't have to navigate this alone. Many families want to understand this risk - your care team can help you talk through it with sensitivity and practical safety planning.

~50%

of deaths are SUDEP

6.1

overall mortality rate*

2.8

SUDEP-specific rate*

9.8 yrs

median age at SUDEP

*Per 1,000 person-years. Sources: Donnan 2023; Moro 2026; Devinsky 2016

You Are Not Alone



A Marathon Journey

Raising a child with a DEE is a long journey. It is okay to feel tired, overwhelmed, or stressed.



Strength in Community

You are part of a large, supportive community of families who truly understand your path.



Your Feelings are Valid

Caregiving impacts your work, relationships, and personal time. Acknowledging this is the first step.



Finding Fulfillment

Many parents find that this journey also brings deep personal growth and unexpected joy.

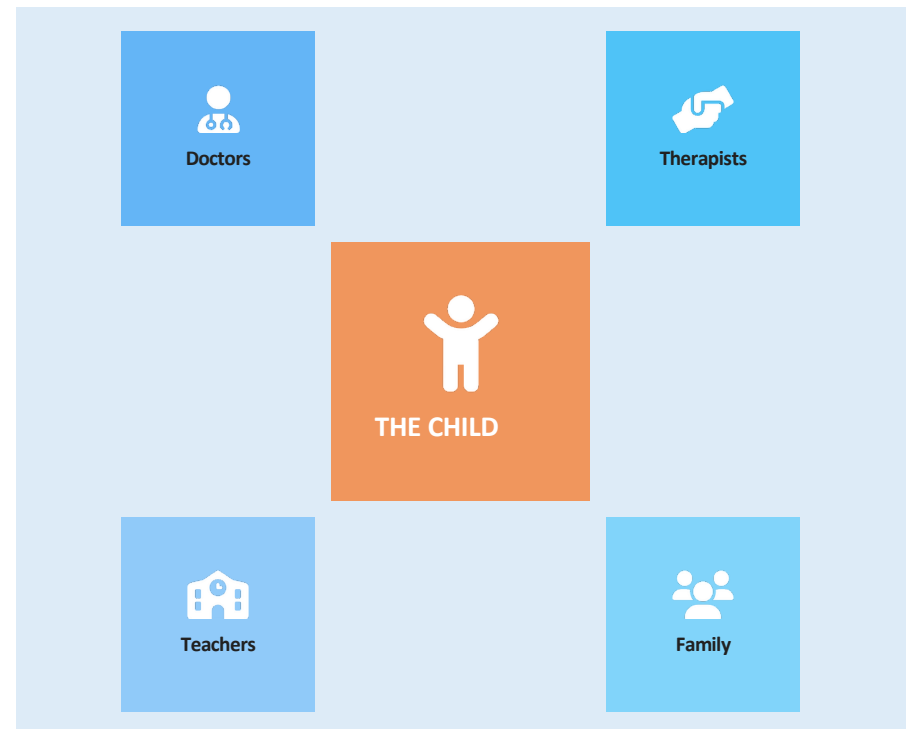
The "Team" Approach to Care

A whole village. Because DEEs affect many parts of life, no single person has all the answers.

Working together. The best care comes from a team of doctors, therapists, and teachers.

Family at the center. You are the most important member of the team and the expert on your child.

Sources: Vasquez 2025; Vigeveno 2013; Porto 2024; Samanta 2025



Thinking About Epilepsy Surgery

A powerful tool. For many children, surgery can significantly reduce or even stop seizures.

Brain focus. When seizures are controlled, the brain can focus better on learning and growing.

Positive outcomes. Many children see their development stabilize or even speed up after surgery.

Quality of life. The goal is always to improve daily life for the child and the whole family.

