

EPILEPSY TOOLKIT

Developmental and Epileptic Encephalopathy (DEE)



We know a new diagnosis of seizures and epilepsy can feel overwhelming, even more so if you or a loved one are diagnosed with a rare, severe, complex and/or medication-resistant epilepsy. These epilepsies are often referred to as Developmental and Epileptic Encephalopathies, or DEEs for short. The [Epilepsy Foundation](#) and our [rare epilepsy partners](#) want you to know that you have our support. *You do not have to manage a new diagnosis of complex epilepsy alone.* We are here to answer questions, provide you with the best resources, and help you connect with other families who have faced the challenges a new epilepsy diagnosis can bring.

This toolkit was designed with you and your family in mind - to help you navigate a new **Developmental and Epileptic Encephalopathy (DEE)** diagnosis and to help you understand the steps you can take to ensure you are getting the care and support your loved one and family need.

Section 1: Understanding Seizures, Epilepsy, and DEE

DEE refers to a group of severe epilepsies that include both seizures (often medication-resistant) and developmental delays. It can feel overwhelming to take in all this new information. Reading through this section will help you better understand seizure types and epilepsy syndromes most frequently associated with DEEs.

What is epilepsy?

What is an epilepsy syndrome?

What is DEE?

What are causes of DEE?

What are the different types of seizures?

Section 2: Your DEE Health Care Team

Managing DEE requires teamwork between members of your health-care team and your family. An important first step is ensuring you have a health-care team that will provide you with the medical expertise you need to accurately diagnose and treat DEE. If your loved one has not responded to two anti-seizure medicines, it is appropriate to seek specialized epilepsy care from an epileptologist at a comprehensive epilepsy center. Equally important is learning how to communicate with your health-care team so that you can participate in important treatment, seizure management, and support decisions that influence your loved one's health and wellbeing from day to day. Additionally, the Epilepsy Foundation Toolbox contains information on seizures and epilepsy, medication, wellness, seizure first aid and more.

Get started here:

[DEE care teams: who are they?](#)

[Find an epilepsy center](#)

[Epilepsy Foundation toolbox](#)

Section 3: Diagnosing DEE

Obtaining a timely, accurate, and specific epilepsy diagnosis is critical and may inform your loved one's treatment and care. The epilepsy field is rapidly changing and access to genetic and other testing is readily available. The evaluation for a new diagnosis of DEE will focus on identifying possible underlying causes, assessing current seizures, finding other medical or psychosocial issues which may be present, and determining the best possible treatment options. A key part of the evaluation will be meeting with your loved one's neurologist and discussing their medical, developmental, and seizure history. Reading through this section will help you better understand specific tests used to evaluate epilepsy including genetic testing, EEGs, and brain imaging.

Evaluation for a new
DEE diagnosis

Brain imaging studies

Genetic testing

EEG and video EEG

Section 4: DEE Treatment Considerations

The treatment for DEEs vary for each person depending on many factors. Obtaining an accurate and specific underlying diagnosis may inform treatments to try and those to avoid. In general, anti-seizure medication is almost always the first-line of treatment for epilepsy. Seizures in DEE can be difficult to control with anti-seizure medicines and often require consideration of other available epilepsy treatments. Read through this section to learn more about different types of medical, surgical, neuromodulation, and dietary treatments available to help control seizures. But, keep in mind that some DEEs may not respond to any treatments. Learn more about underlying causes of epilepsy and how treatments might vary accordingly. Learn about the importance of securing Rescue Therapies for breakthrough, long-lasting and/or cluster seizures which may occur frequently in people with DEEs.

[Epilepsy causes & their treatments](#)

[Anti-seizure medications](#)

[Rescue therapies](#)

[Medication considerations in children](#)

[Surgical treatments](#)

[Treatment devices](#)

[Dietary treatments](#)

Section 5: Challenges in DEE

A DEE diagnosis may bring many different challenges. These may be related to difficult-to-control seizures and the associated risks. People diagnosed with DEEs are at higher risk of status epilepticus and Sudden Unexpected Death from Epilepsy (SUDEP). Learning about these risks as well as taking precautions to avoid or manage them are especially important for those diagnosed with DEEs. Seizure alert devices are described as one tool to help detect seizures and expedite care.

Beyond seizures, non-seizure symptoms can be even more disruptive to quality of life than the seizures themselves. These may include intellectual disability, movement disorders, respiratory disorders, sleep, and more. Read this section to learn about common problems that are seen in people with DEE.

[Status Epilepticus](#)

[SUDEP risk](#)

[Common non-seizure challenges](#)

[Seizure alert devices](#)

Section 6: Resources and Support for DEE

Building a network of support for your loved one with DEE and your family is important. Read through this section to learn more about resources for learning, advocacy, building peer and sibling support networks, and connecting with your local Epilepsy Foundation office, and the national Epilepsy Foundation's 24/7 Helpline. Additionally, the Rare Epilepsy Network (REN) is a community of 70+ rare epilepsy organizations each one focused on a unique underlying cause of epilepsy. If your loved one has a specific rare epilepsy diagnosis, visit the REN to see if there is a patient advocacy organization or support group offering tailored information, education, support, and community. Included below you will find connections to reputable partners who provide resources and support for the DEE community.

Resource & early intervention services

Epilepsy Foundation 24/7 Helpline

Local Epilepsy Foundation support

Rare Epilepsy Network

DEE-p connections

Child Neurology Foundation

American Academy of Pediatrics

Family finances

Pediatric palliative care