Timely Diagnosis *and* Treatment *of* Developmental *and* Epileptic Encephalopathies (DEEs)

A CARE COMPANION CHECKLIST

DEE BACKGROUND

Definitions

- Epileptic encephalopathy—epileptic activity leads to abnormal function
- Developmental encephalopathy—genetic disorder or other altered brain function leads to abnormal function
- Sometimes BOTH are present and can contribute to the overall picture

The exact number of DEEs isn't known

DEEs encompass a wide spectrum of conditions

More than 900 genes and structural causes have been identified

Stay vigilant with care transitions as a patient moves into adulthood

DEEs tend to

- Start at consistent ages, depending on syndrome
- May stop at certain ages
- Respond (or not) to medications in an expected fashion
- Have similar types of seizures
- Be correlated with specific comorbidities (eg, intellectual challenges, anxiety, depression, autism)

DEEs include specific epilepsy syndromes such as

- Dravet syndrome
- Febrile infection-related epilepsy syndrome
- Infantile epileptic spasms syndrome
- Landau-Kleffner syndrome
- Lennox-Gastaut syndrome
- Tuberous sclerosis complex
- Many others

QUESTIONS FOR YOUR CLINICIAN

DIAGNOSIS/IDENTIFICATION

- What is the difference between epilepsy and seizures?
- What causes seizures? Is it always a problem with the brain?
- How do you distinguish between the varying types of DEEs?
- Do DEEs always start in infants or young children, or can they start in adults?

ASSESSMENT

- Do I need a genetic test?
- Do I need blood tests?
- Do I need imaging (eg, x-rays, magnetic resonance imaging [MRI], computed tomography [CT], positron emission tomography [PET], electroencephalogram [EEG])?
- Do I need tests for cognitive and physical function?

TREATMENT

- How do we decide what treatment to use?
- Is the list of treatments similar for all DEEs?
- Do medications treat the symptoms or "fix" the disease?
- What can we use besides medication?
- Does a DEE get worse over time without treatment?

MOVING FORWARD

- Will the seizures ever resolve on their own?
- What is care "transition"?
- Are there support groups for people with a DEE?
- What are some ways I can "live my best life"?

References

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