

COULD IT BE DRAVET?

A Diagnosis Guide for Healthcare Professionals

DRAVET SYNDROME

A rare, life-long and life-limiting neurological condition, encompassing treatment-resistant epilepsy, intellectual disability and a spectrum of associated comorbidities, which may include autism, ADHD, behaviours that challenge and difficulties with speech, mobility, eating and sleep. There is also an increased risk of SUDEP with Dravet Syndrome (15% higher than other childhood-onset epilepsies). Getting the right treatment in place can help reduce the risk of SUDEP.

DIAGNOSING DRAVET

Dravet Syndrome is a clinical diagnosis based on its typical features. A genetic test can confirm diagnosis and is available via the NHS. Diagnosis at any age - including late adulthood - has significant benefits, enabling effective treatment and improving quality of life.



SIGNS OF DRAVET

Seizure onset in infancy

- Typically between 3-9 months
- Seizures are frequent, usually febrile, often hemi-clonic, often prolonged with status epilepticus
- Neurological examination is normal at onset
- EEG normal for first 1-2 years

Prolonged seizures in infancy are a sign of Dravet Syndrome; don't dismiss prolonged febrile seizures - check for Dravet.

Development slows after year 1

- Walk a little later (e.g. 17-18 months), unsteady for longer
- Language slower to acquire
- Over time, most develop intellectual disability ranging from severe (50%) to mild

With age, seizure patterns change, comorbidities occur

- Seizures are unpredictable and treatment resistant
- Night-time seizures common as children become older
- Most develop subtle pyramidal signs and gait disorders by late childhood to adolescence
- Many experience behaviour and motor disorder; ADHD and/or autistic traits are common
- Seizures continue throughout adulthood

WHAT TO DO IF YOU SUSPECT DRAVET SYNDROME

1

Avoid sodium channel blockers

Exercise caution with carbamazepine, gabapentin, lamotrigine, oxcarbazepine, phenytoin, pregabalin, tiagabine, and vigabatrin. These medications can make seizures worse. Prolonged use can increase the risk of poorer intellectual outcomes.

2

Refer for genetic testing

Genetic testing (with counselling) has benefits at any age. The right diagnosis and treatment can reduce seizure and disease burden even in intractable adult patients. Even if the test is negative, don't rule out Dravet Syndrome if the patient fits the clinical diagnosis.

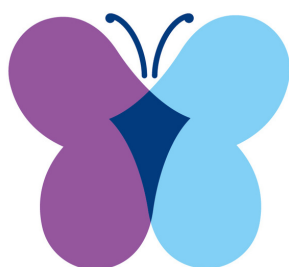
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Signpost to DSUK for support

Dravet Syndrome UK is an independent UK charity dedicated to improving the lives of those affected by this devastating condition. We provide practical and emotional support, educate and raise awareness, and fund novel research.

FOR MORE INFORMATION VISIT

WWW.DRAVET.ORG.UK



DRAVET
Syndrome UK

Hope for families with life-limiting epilepsy