5. Fostering a Supportive Environment

Continuity of Care

When the child transitions to a new classroom or school year, it is vital that new staff spend time with them and their family. Thorough handovers are essential to ensure a smooth transition and continuity of care.

Eating and Nutrition

Many children with Dravet Syndrome have eating difficulties. Rigid eating schedules may not be effective. If the child indicates they are hungry, it is best to allow and encourage them to eat, regardless of the time.

Children can have eating difficulties for various reasons, including sensory issues. Always talk with families to get a complete picture of the child's eating needs.

Communication with Parents

A strong partnership between the school and the family is key. Good communication is vital. We recommend a daily home diary to facilitate a clear handover at drop-off and pick-up, ensuring everyone is up to date on the child's well-being.

Inclusion

With careful planning such as carrying out a thorough risk assessment, a child with Dravet Syndrome can and should participate in all school activities. They should never have to miss out on events or lessons. Inclusion is essential for their social and emotional development.

Ongoing Training

It is crucial for all staff to receive yearly training that is specific to the child's needs. This should include:

- **Epilepsy and Dravet Syndrome Awareness Training**
- **Emergency Medication Administration** (e.g., buccal midazolam or rectal diazepam)
- **Oxygen and Suction Training** (if required)
- **Training on Feeding** (if required)
- **First Aid Training**

DRAVET
Syndrome UK

Dedicated to improving the lives of those affected by Dravet Syndrome

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Supporting a Child with Dravet Syndrome

A Guide for Teachers and TAs

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About your School Pack

This pack is a resource to help create a safe, supportive, and inclusive learning environment where the child can thrive. Your commitment to understanding and supporting them is deeply appreciated.

For more information visit our website **dravet.org.uk**

Or contact us directly via email **info@dravet.org.uk**

1. Understanding Dravet Syndrome

What it is

Dravet Syndrome is a severe, lifelong form of epilepsy that begins in infancy. It is a developmental and epileptic encephalopathy, which means that the seizures and the underlying genetic condition significantly affect brain development and function.

Why it's different

Unlike many other forms of epilepsy, Dravet Syndrome is often resistant to standard epilepsy medications. Seizures are frequently triggered by fever, a change in body temperature, or over-exertion. The condition also comes with significant comorbidities—related health and developmental issues—that are not typical of other epilepsies.

2. Key Medical and Developmental Considerations

Comorbidities (co-occurring conditions)

A child with Dravet Syndrome may also experience a range of other challenges, including intellectual disability, autism-like traits, ADHD, sleep disturbances, gait and movement difficulties, and eating issues. It's crucial to understand these co-occurring conditions as part of the overall care.

Seizure Triggers

Common triggers include illness or fever, changes in body temperature (from warm baths, hot weather, or exercise), excitement or emotional stress, lack of sleep, and photosensitivity (flashing lights or patterns).

Seizure Types

A child may experience various types of seizures, including prolonged tonic-clonic seizures, which involve muscle stiffening and jerking; myoclonic seizures, which are brief, shock-like muscle jerks; and atypical absence seizures, which involve a lapse in consciousness.

3. Proactive Planning and Management

Individual Care Plan (ICP)

The child's care plan is the most important document for all staff. It should be read and understood by every person who will interact with the child. This plan details seizure types, triggers, and the specific emergency procedures to follow.

Environmental Safety and Accessibility

Always assess the environment for potential dangers. This includes avoiding situations where the child might be near open water or at height, such as on or near stairs, whenever possible.

It is critical to ensure that a staff member can easily and quickly reach the child at all times to administer emergency medication if a seizure occurs. This consideration should be part of all class and outing plans.

Climate and Temperature Control

Because temperature changes are a significant seizure trigger, it's essential to manage the child's environment. We strongly recommend that the school consider purchasing a portable air conditioning unit that can move with the child to different classrooms or areas.

Learning and Academic Support

Seizures and medications can affect a child's learning and memory. To support them, focus on short, high-quality learning sessions and use repetition to help with information retention.

Scheduled Naps

Many children with Dravet Syndrome need to take naps during the school day to prevent seizures. A child should never be left alone while napping. This is a critical safety measure, especially given the risk of SUDEP (Sudden Unexpected Death in Epilepsy), which is a serious concern.

4. Emergency and Post-Seizure Protocols

Seizure Action Plan

Every staff member must know their role during a seizure. This should be a clear, concise plan.

Example:

Staff 1: Attends to the child, administers emergency medications, and provides first aid.

Staff 2: Ensures the safety of other students by escorting them out of the classroom or to a designated safe area.

Staff 3: Calls the emergency services.

Post-Seizure Care

After a seizure, it is important to check in with everyone—both students and staff—as seizures can be very frightening.

Record the details of the seizure, including duration, type, and any potential triggers. This information is vital for the medical team to identify patterns and adjust care. Ensure that this information is always shared with parents and included in the home diary.