

Information for Schools: Heat Sensitivity and Temperature Regulation in Pupils with Dravet Syndrome

Re: Supporting a pupil with Dravet Syndrome during hot weather and periods of temperature change

Dear Teaching Professional,

We are writing on behalf of Dravet Syndrome UK to provide important information regarding the impact of heat and temperature changes on children and young people living with Dravet Syndrome.

Dravet Syndrome is a rare, severe developmental and epileptic encephalopathy. Many individuals with Dravet Syndrome experience significant difficulties regulating their body temperature and are particularly vulnerable to seizures triggered by heat, overheating, fever, physical exertion, and sudden changes in temperature. Sudden changes in temperature can also relate to becoming too cold for instance very cold paddling pools or air conditioning.

While every individual is different, temperature related issues are a common seizure trigger reported by families affected by Dravet Syndrome.

Children with Dravet Syndrome may be unable to regulate their body temperature effectively. Even relatively small increases in body temperature can increase the risk of seizures.

Potential triggers include:

- Hot classrooms or poorly ventilated environments
- Outdoor activities during warm weather
- Sports days and physical education lessons
- Direct sunlight and prolonged exposure to heat
- School trips involving walking or outdoor activities
- Hot school transport
- Warm swimming pool environments
- Sudden temperature changes, such as moving from an air-conditioned room into extreme heat

We would ask every school to make reasonable adjustments with regards to the extreme temperatures this week, in order to keep those children living with Dravet Syndrome in school safe and well. The reasonable adjustments should enable children to join in wherever possible, but may also enable you to make adjustments to the child's school day itself.

Exposure to excessive heat or rapid temperature changes may result in:

- Increased seizure frequency
- Prolonged seizures
- Increased fatigue and reduced concentration
- Difficulties with balance, coordination, and mobility
- Behavioural changes

It may be helpful to consider the following:

- Ensure classrooms are well ventilated.
- Use fans, air conditioning, or cooling measures where available - ensuring they are not too cold resulting in a drastic change in temperature.
- Allow the pupil to sit in cooler areas of the classroom.
- Permit unrestricted access to water throughout the day.
- Encourage regular drinking, particularly during warm weather.
- Consider modifying or reducing participation in PE, sports days, outdoor learning, and other strenuous activities during hot conditions.
- Allow rest breaks whenever needed.
- Follow any individual healthcare plan recommendations.

Families often become experts in understanding their child's specific temperature sensitivities. We strongly encourage schools to work closely with parents or carers to identify effective strategies and reasonable adjustments that enable the pupil to participate safely in school life.

By recognising the risks associated with heat and temperature changes, schools can play a vital role in reducing seizure triggers and helping pupils with Dravet Syndrome remain safe, healthy, and included.

Please note this information is intended to complement, not replace, an individual's healthcare and epilepsy management plans.

If your school would like further information, advice, or support regarding Dravet Syndrome please do not hesitate to contact Dravet Syndrome UK. We are always happy to assist schools in developing appropriate strategies and reasonable adjustments that help children and young people with Dravet Syndrome thrive at school.

Thank you for your support and understanding.

Yours faithfully,

Dravet Syndrome UK
Supporting families affected by Dravet Syndrome