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TO WHOM IT MAY CONCERN

Advice to Schools During Periods of Extreme Heat for Pupils Affected by Ectodermal Dysplasia

We are currently experiencing exceptionally high temperatures across many parts of the UK. The Ectodermal Dysplasia Society has a duty of care to the children, families and individuals we support and is therefore issuing this guidance to schools regarding pupils affected by Ectodermal Dysplasia (ED).

Many children affected by ED, particularly those affected by Hypohidrotic Ectodermal Dysplasia (HED), are unable to regulate their body temperature effectively due to absent or non-functioning sweat glands. As a result, they are at significant risk of overheating (hyperthermia), which can develop rapidly and become a serious medical emergency.

Unlike their peers, children with ED cannot rely on their bodies to cool themselves naturally. Once their core body temperature begins to rise, they may experience headache, dizziness, fatigue, poor concentration, confusion, behavioural changes, reduced coordination, nausea and, in severe cases, seizures, loss of consciousness or other life-threatening complications.

During periods of exceptionally hot weather, children affected by ED face a substantially increased risk of overheating and heat-related illness compared with their peers. Whilst Department for Education guidance advises that schools do not normally close during hot weather, such guidance is intended for the general school population and does not specifically address the needs of children who are unable to regulate their body temperature due to a rare medical condition.

For children affected by ED, remaining in school during periods of extreme heat may present a significant risk to their health and wellbeing. The ED Society therefore encourages schools to work closely with families, assess each child's circumstances individually and ensure that health and safety considerations take precedence where there is a risk of overheating.

For some children, particularly where effective temperature control cannot be guaranteed throughout the school day, remaining at home in a cool, controlled environment may be the safest option until temperatures reduce. We would therefore ask schools to exercise discretion regarding attendance and not penalise children or families where absence is directly related to managing the risks associated with ED and exceptionally hot weather. Parents should be supported in making decisions that are necessary to protect their child's health and safety.

The safety and wellbeing of the child must remain the overriding consideration. Whilst education is extremely important, children who are becoming overheated are unlikely to be able to concentrate,

learn effectively or fully participate in school activities. Preventing a medical emergency must always take precedence over attendance targets.

Further Government guidance for schools can be found at:

[Looking after children and those in early years settings before and during hot weather: teachers and other educational professionals](#)

Where a child affected by ED attends school during periods of hot weather, every effort should be made to minimise the risk of overheating. Schools should ensure that all provisions outlined within the child's Individual Healthcare Plan are followed and that staff remain vigilant for any signs of temperature dysregulation.

Recommended measures include:

- Ensuring access to a cool, well-ventilated environment at all times.
- Keeping fans, air-cooling units or air conditioning operating where available.
- Seating the child away from direct sunlight, windows and other heat sources.
- Encouraging regular fluid intake throughout the day.
- Providing frequent cooling breaks, particularly after physical activity.
- Using cooling aids such as gel packs, cooling pads, spray water bottles, wet cloths and cooling garments where appropriate.
- Allowing removal of jumpers, blazers, ties or other unnecessary layers of clothing.
- Modifying, postponing or withdrawing participation from outdoor activities, PE lessons, sports days and other physically demanding activities where necessary to prevent overheating.
- Ensuring the child is never left alone if they report feeling hot or show signs of overheating.
- Taking immediate action at the first indication that the child's temperature may be rising.

Children affected by ED may not always recognise that they are becoming dangerously overheated until their symptoms are already affecting concentration, behaviour, coordination and decision-making. For this reason, prevention and early intervention are essential.

The ED Society fully supports children affected by ED participating in education, sport and all aspects of school life wherever it is safe to do so. However, during periods of exceptionally hot weather, schools may need to make reasonable adjustments and adopt a flexible approach to ensure that children affected by ED remain safe and well.

The safety and wellbeing of the child must remain the overriding consideration. During periods of exceptionally hot weather, flexibility, understanding and close partnership working between schools and families are vital to ensuring that children affected by Ectodermal Dysplasia remain safe whilst continuing to access education wherever possible.

Diana Perry

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