

A template letter for the teachers of siblings who have a brother or sister with Dravet Syndrome

To the teacher of my son/daughter, the sibling of a special needs child:

I wanted to make you aware of our situation at home, a situation that could, at times, affect his/her school life as well. Our son/daughter is the sibling to a child with complex needs. Her sister/brother has a rare type of epilepsy called Dravet Syndrome.

Children with Dravet Syndrome experience severe, potentially life-threatening seizures. They also have varying degrees of intellectual disability, autism, behavioural problems, and difficulties with speech, mobility, feeding and sleep.

Seizures can happen at anytime during the day or night and unfortunately often require emergency medication. What this means for our family is that our ordinary routine can often be disrupted.

For example, there could be nights when we had planned to help with homework, but ended up on an ambulance ride taking their brother/sister to A&E instead.

There could be exhausting times where we arrive at school late because we didn't get home from hospital until late the night before. There could be mornings when we had intended to make lunches, but a seizure struck before we could make it that far.

There could be evenings where our son/daughter is abruptly removed from home to stay with someone, because we had to make an unplanned rush to the hospital. There could even be times when we're out of town for specialist appointments and so the normality of life is a bit off.

All of this means that our son/daughter may show up to school extra anxious, or scared, or tired. Or missing papers he/she should have. Or homework. Or a lunch box.

Sometimes you may observe him/her a bit more on edge. Or more sensitive to situations that should not cause tears, but do.

We are crossing our fingers and hoping that these difficult days are few and far between, but as our child's teacher(s), we feel it is valuable for you to be aware of this burden that he/she often carries.

Most of the time our son/daughter handles all of this so well and there is a possibility you might not even notice a difference on the hard days. We hope that is the case! But in the circumstance where it is not, we just want you to know and understand the reasons for this.

If you would like to know more about Dravet Syndrome, there's lots of useful information on www.dravet.org.uk.

Thank you for investing in the life of our child this year!