

To the teachers of my child,

You may already know my child or be about to meet them, and I'd like to share a little about our family circumstances. At home, they are the sibling of a child with complex medical needs, and this can sometimes affect their experience at school.

Their brother/sister has a rare neurological condition called Sturge Weber Syndrome. It's likely you haven't heard of it before—we hadn't either until their diagnosis. Children with Sturge Weber Syndrome can experience life-threatening seizures, developmental delays, cognitive challenges, and may also be affected by autism, ADHD, behavioural difficulties, and sleep disturbances.

Seizures can happen at any time—day or night—and often require emergency medication or hospitalisation. This unpredictability can disrupt our routines and sometimes means our child takes on more responsibility at home, stays with others during emergencies, or travels with us for specialist appointments.

As a result, there may be days when our child is:

- Tired or emotionally withdrawn
- Anxious or distracted
- Forgetful about homework, PE kits, or deadlines
- More sensitive or reactive than usual

We kindly ask that any concerns be approached with understanding and, where possible, discussed with us or with our child gently. They are navigating a unique and often demanding role as a young carer, and your support can make a big difference.

Despite these challenges, our child is resilient and often manages incredibly well. You may not notice anything unusual, but we wanted you to be aware of what might be happening behind the scenes.

If you'd like to learn more about Sturge Weber Syndrome, please visit www.sturgeweber.org.uk.

We also welcome any additional support the school can offer—whether through pastoral care, young carers programmes, or sibling support groups.

Thank you for taking the time to read this. Please don't hesitate to reach out if you'd like to talk further or explore ways we can work together to support our child.

Warm regards,