



Sturge Weber UK – School Information Pack

Supporting Children and Young People with Sturge Weber Syndrome

About Sturge Weber Syndrome (SWS)

Sturge Weber Syndrome is a rare neurological condition that can affect:

- The skin (port-wine stain birthmark)
- The brain (causing seizures or learning difficulties)
- The eyes (glaucoma or vision problems)

Every person with SWS is different. Some may need extra support, while others may not.

Starting Nursery, School, or College

Transitions can be exciting but also challenging. This pack helps staff understand how to support a student with SWS.

What Staff Should Know

- Medical Needs: Some students may have epilepsy, vision issues, or fatigue. A care plan should be in place.
- Learning Support: Some may need help with concentration, memory, or processing information.
- Emotional Support: Changes in routine or environment can be stressful. A calm, consistent approach helps.
- Communication: Keep parents/carers informed and involved in planning and support.

Practical Tips for Staff

- Have a Health Care Plan and know what to do in case of a seizure.
- Use visual aids and clear instructions.
- Allow extra time for tasks if needed.
- Provide a quiet space for rest or recovery.
- Encourage peer understanding and inclusion.

What to Include in the Student's File

- Emergency contact and medical information
- Individual Health Care Plan
- Education, Health and Care Plan (EHCP) if applicable
- Notes on learning style and support strategies



- Communication preferences



Working Together

- Parents/Carers: Key partners in sharing insights and updates.
- Health Professionals: May include neurologists, ophthalmologists, or therapists.
- Charity Support: Sturge Weber UK can provide resources and advice.



Health and Safety in School

- Ensure staff are trained in seizure response and first aid.
- Keep emergency medication accessible and clearly labelled.
- Have a quiet space available for recovery or rest.



Staff Training and Awareness

- Provide basic training on SWS for all staff.
- Share the student's individual needs and care plan.
- Encourage empathy and understanding among staff and peers.



Inclusion and Participation

- Adapt activities to ensure full participation.
- Use inclusive language and avoid assumptions.
- Celebrate differences and promote peer support.



Transition Support

- Plan ahead for transitions between year groups or schools.
- Offer visits and visual guides before starting.
- Assign a key adult for support during the transition.



Learning and Curriculum Access

- Use differentiated teaching strategies.
- Provide assistive technology if needed.
- Regularly review progress and adapt support.



Contact Us

Sturge Weber UK



Milk Hall, Withens Lane, Barkisland, HX4 0DY



www.sturgeweber.org.uk



support@sturgeweber.org.uk