

A practical guide for supporting pupils with Ehlers-Danlos syndromes (EDS) and Hypermobility Spectrum Disorder (HSD)

Audience: SENCOs, teachers, teaching assistants, pastoral teams, school leaders and college staff.

How to use this guide

EDS and HSD affect every pupil differently. This resource is designed to help schools identify common barriers to learning, consider practical adjustments, and understand the outcomes those adjustments may support. Not every adjustment will be appropriate for every pupil. Support should always be individualised and developed in partnership with the pupil, family and relevant healthcare professionals.

At a glance

Many pupils with EDS or HSD may experience:

- Fatigue
- Pain
- Joint instability
- Difficulties with handwriting and fine motor skills
- Dizziness or fainting
- Gastrointestinal or bladder symptoms
- Anxiety or emotional wellbeing challenges
- Difficulties attending school consistently
- Challenges participating in PE or practical activities

Many of these symptoms are invisible and may fluctuate from day to day.

Key message for schools

The most effective support is usually not complex.

Small, practical adjustments that reduce fatigue, pain, anxiety and physical demands can have a significant impact on attendance, participation, wellbeing and educational outcomes.

When schools, families and pupils work together, young people with EDS and HSD are more likely to thrive academically, socially and emotionally.

Topic	Barrier to Learning / What You Might See	Reasonable Adjustments	Intended Outcome
Fatigue	Difficulty concentrating, reduced stamina, slower working speed, falling asleep in lessons, worsening symptoms throughout the day, difficulty completing work.	Planned rest breaks; flexible deadlines; reduced copying from boards; access to lesson materials electronically; seating near teaching staff; flexible timetables where needed; reduced homework during symptom flares; access to water and snacks; access to a quiet space.	Improved concentration; better engagement with learning; reduced symptom escalation; increased attendance and participation; improved wellbeing.
Pain	Frequent changes in position, difficulty remaining seated, reduced participation, slower work completion, pain-related absences, reduced concentration.	Flexible seating; movement breaks; standing desk or alternative workstation; pain management plan; reduced carrying of heavy equipment; additional time to move between lessons; lift access where available.	Improved comfort; increased participation; better concentration; reduced fatigue and pain flare-ups.
Handwriting and Fine Motor Difficulties	Slow handwriting, hand pain, reduced written output, fatigue when writing, poor pencil control, difficulty using classroom equipment.	Laptop or tablet access; touch typing support; reduced copying tasks; printed notes; alternative recording methods; scribe support where appropriate; pencil grips or adapted equipment; additional time for written work..	Improved access to learning; increased independence; reduced pain and fatigue; more accurate demonstration of knowledge and understanding.
Joint Instability and Mobility Difficulties	Clumsiness, frequent trips or falls, joint pain, difficulty carrying equipment, reluctance to use stairs, difficulty standing for long periods.	Lift access where available; reduced carrying requirements; second set of books; flexible movement around site; adapted evacuation plans if required; seating adjustments; early classroom access to avoid crowded corridors.	Increased safety; reduced injury risk; improved confidence; better participation in school life.
Dizziness, PoTS Symptoms and Fainting	Dizziness, light-headedness, headaches, reduced concentration, visual disturbances, fainting episodes.	Easy access to water; permission to sit or lie down when needed; flexible transition times; staff awareness of symptom management plans; avoiding prolonged standing; access to cool and well-ventilated spaces.	Reduced symptom escalation; improved participation; increased safety; greater confidence in managing symptoms independently.
Toileting needs	Frequent toilet use, urgent toilet access, anxiety about accessing toilets, reduced concentration due to symptoms.	Toilet pass; discreet arrangements; flexible lesson exits; staff awareness of agreed arrangements; access to nearby toilets where possible.	Reduced anxiety; improved dignity; increased classroom engagement; better symptom management.
Attendance and medical appointments	Frequent absence, late arrival, part-day attendance, reduced participation during symptom flares, multiple healthcare appointments.	Flexible attendance support; access to learning materials remotely; catch-up plans; prioritised curriculum content; alternative deadlines; communication plan between home and school.	Improved educational engagement; reduced stress; better continuity of learning; increased school connection and belonging
Physical Education and School Activities	Pain after exercise, fatigue following activity, frequent injuries, reluctance to participate, difficulty with high-impact activities.	Adapted activities; flexible participation; alternative roles within PE lessons; individual pacing; rest opportunities; risk assessments for trips and activities.	Continued inclusion; improved confidence; safer participation; reduced injury risk.

Emotional Wellbeing and Anxiety	School avoidance, anxiety, reduced confidence, emotional distress, social isolation.	Trusted adult; regular check-ins; quiet space access; flexible support during difficult periods; support with transitions and change; peer awareness where appropriate and agreed.	Improved emotional wellbeing; increased confidence; better engagement with school; reduced anxiety-related absence.
Neurodivergence and Sensory Differences	Difficulty processing information, sensory overwhelm, anxiety around change, communication differences, executive functioning challenges.	Predictable routines; clear instructions; sensory considerations; processing time; visual supports; flexible communication approaches; reduced sensory demands where possible.	Improved learning engagement; reduced anxiety; greater independence; improved access to the curriculum.
Carrying Equipment and Moving Around School	Pain, fatigue, joint instability, difficulty carrying books or equipment between lessons.	Second set of books; digital resources; locker access; reduced carrying expectations; support moving equipment where needed.	Reduced physical strain; improved energy levels for learning; increased independence and participation.
Examinations and Assessments	Fatigue, pain, handwriting difficulties, reduced concentration, slower processing speed.	Access arrangements where appropriate; rest breaks; word processor; separate room; modified timetable; ergonomic seating; extra time if approved.	Fairer assessment of knowledge and skills; reduced fatigue; improved ability to demonstrate attainment.
Lunchtimes, Breaktimes and Social Participation	Fatigue, pain, mobility difficulties, social isolation, anxiety.	Access to quieter spaces; supervised indoor options; seating availability; support with social inclusion; flexibility around queues and movement.	Improved wellbeing; greater social inclusion; reduced fatigue; increased enjoyment of school life.
School Trips and Educational Visits	Concerns around walking distances, fatigue, toileting needs, pain, participation in activities.	Early planning with family; individual risk assessment; transport adjustments; access to rest breaks; flexibility in activities; support with medication or healthcare plans.	Increased inclusion; safer participation; access to enrichment opportunities alongside peers.
Fluctuating Symptoms	Good days and difficult days, changing levels of fatigue, pain or mobility, inconsistent presentation.	Flexible and responsive support plans; regular review meetings; staff awareness that symptoms can vary significantly day to day.	Consistent support; reduced misunderstanding; improved educational engagement and wellbeing.