Support for education professionals

You can find all of this information and links to downloadable resources ehlers-danlos.uk.

This toolkit has been designed to give educational staff practical guidance for schools, colleges and educational settings.

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

How to use this guide

EDS and HSD affect every student differently. No two students will be affected in the same way. Support should always be based on the individual child's needs rather than their diagnosis alone.

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 student. Support should always be individualised and developed in partnership with the student, family and relevant healthcare professionals.

EDS and HSD can affect attendance, concentration, fatigue, mobility, handwriting, emotional wellbeing and participation in school life. Small adjustments can make a significant difference.

This toolkit helps educational professionals understand common barriers and identify practical support strategies.

Key facts

- EDS and HSD are lifelong conditions that affect connective tissue throughout the body.
- Hypermobility is quite common in the general population, particularly in children and is not usually a problem on its own.
- Symptoms vary significantly between students.
- Many students look well despite experiencing significant symptoms and may cause problems for students at school and these are likely to occur before a diagnosis has been given.
- Particularly severe symptoms may affect a students attendance, as will the frequent medical appointments which often come with having the conditions.
- Research has shown that people who are hypermobile are more likely to be anxious than non-hypermobile people
- Difficulties often occur before a diagnosis has been confirmed.
- Fatigue, pain and mobility challenges can affect learning and attendance.
- Reasonable adjustments can help students participate fully in education.
- Students may require support from multiple professionals and services.
- Students with EDS or HSD often fidget
- Because a student with EDS may be tired, tearful, and bruise easily due to fragile skin, these signs can sometimes be mistaken for indicators of abuse or neglect. This is an important consideration.

What schools need to know

Most schools do not need specialist medical knowledge.

The most important role of education professionals is to:

- recognise barriers to learning
- understand how symptoms may affect education
- make appropriate adjustments
- work collaboratively with students, families and healthcare professionals

It can be tempting to dismiss reports of pain from a student or parent/carer because pain does not always have visible external signs. Pain is extremely complex and can have sensory and physical causes. Being disbelieved can lead to frustration, discourage reporting of pain and undermine trust and the communication needed to successfully navigate supporting the student.

It is important to defer to medical professionals and not to reject a student's self-assessment- "toughing it out" without medical advice is not advised. Where there is no obvious sign of injury, determining whether injury is present is for medical professionals; it is important to collaborate with parents and health professionals so students develop a healthy and supportive approach to dealing with pain.

Students with EDS and HSD should have ready access to the first aid room for when they need help managing their pain or they could be allowed to carry a mobile phone for silent medication alerts. Ideally, they will have a pain management plan in place at school. This might include being allowed to leave lessons to take medication as required or having a system to alert the teacher (using cards) if they need to leave a lesson due to feeling unwell.

Pacing

Pacing is an important part of the self-management of EDS and HSD and can help with fatigue and pain. Effective pacing helps to avoid a boom and bust cycle of energy and fatigue and can enable the student to do more. Various techniques can be used.

Working with a traffic light system can help to manage this well. Dividing activities into three categories depending on the level of energy they take creates a 'traffic light system'. Green is for easier tasks, such as eating lunch. Amber are tasks which take a bit more physical or mental energy, for example writing for a long time or doing a short exam or test. Red tasks take a lot of energy, for example a PE lesson. These tasks are very personal to each individual and can be adjusted as such. There should only be one red task a day as these need time to recover from.

School uniform

Some students may need some flexibility in what they are allowed to wear for school if there is a uniform. For example, braces worn to stabilise joints may be difficult to fit under school trousers or shirts; boots rather than shoes may be needed to support unstable ankle joints. Some students may need to wear orthotics (insoles) in their shoes.

Supportive or compression garments (worn under clothes) are also increasingly being used by people with EDS and HSD. These are useful as they seem to help to improve the sense of where the limbs are in space (proprioception) and may help with other symptoms related to blood circulation.

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. Getting an Occupational Therapist to help with suggestions is recommended.

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

Adjustments

Most children with hypermobility go to school full time and manage just fine with adjustments in place. Being at school can be a great way to be distracted from pain and discomfort. You also get to move around a lot, which is good for helping to manage pain.

However please do remember that students may have comorbidities such as PoTS and gastro issues and may need other adjustments.

Barriers, Adjustments and Outcomes

Many students 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.

Barriers to learning and outcomes

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 and salty snacks; 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.

Signs and symptoms

EDSUK

Common symptoms

Severe tiredness

Neck instability

Difficulty regulating blood pressure

Persistant widespread pain

Pain in fingers and hands

Gut, bowel and bladder problems

Loose joints which dislocate easily, frequent sprains

Fragile, stretchy skin which damages easily or thick, velvety skin

May be seen

Difficulty concentrating

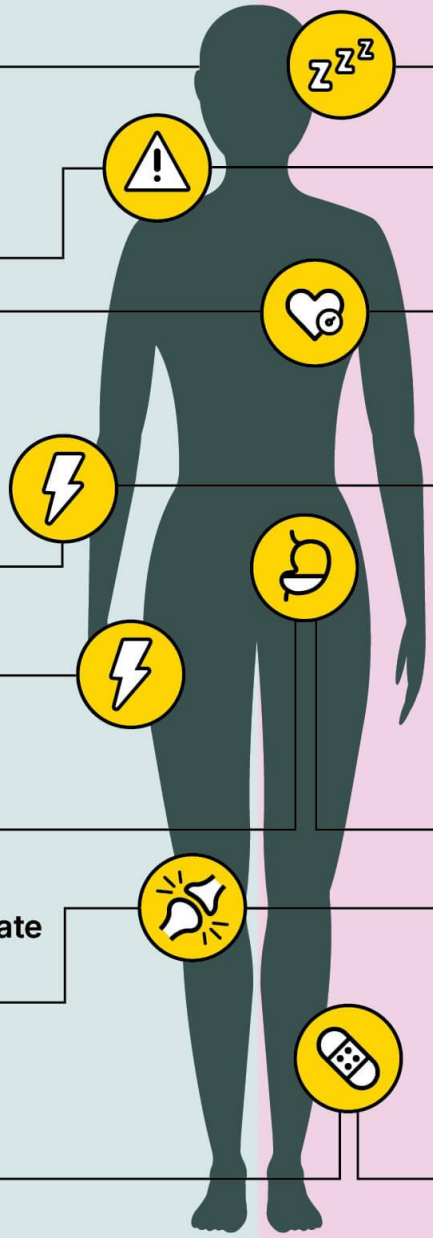
Lightheadedness, dizziness, sweating and fainting, especially when standing; headaches and difficulty concentrating

Difficulty concentrating, fidgeting or wanting to move around a lot

Needing the toilet a lot or not at all

Joint pain or weakness without a clear cause and may appear clumsy

Bruised or scarred skin



For more information, call the Adviceline **0800 907 8518**
or email **adviceline@ehlers-danlos.uk**

@ehlersdanlosuk @ehlersdanlossupportuk

The Ehlers-Danlos Support UK is a charity registered in England and Wales (No. 1157027) and Scotland (SCO46712)
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TOP TIPS

EDSUK

to support a pupil with EDS or HSD

The Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue disorders with symptoms affecting the whole body. It is more common for children and young people to be defined as having joint hypermobility syndrome (JHS) than EDS. Pupils with JHS can display similar symptoms to those with the most common type of EDS. Pupils affected by EDS may face challenges to their physical and mental health.

1 Adjustments

Pupils with JHS or EDS may have symptoms which affect them at school and vary greatly from day to day. The conditions affect individuals differently. Many of the adjustments which benefit pupils with JHS or EDS are simple and low cost.

2 Sitting

Pupils with the conditions may find it difficult to sit in a set position, especially for long periods.

Good posture is important. Providing back support, cushions, beanbags, footrests or the option to stand can reduce discomfort and minimise fidgeting.

3 Physical Education

Pupils are encouraged to take part in appropriate physical activity and sport to facilitate their physical development.

This also helps keep joints in place and improves coordination, muscle strength and stamina. Contact sports are not advised for some pupils. Alternative activities and additional time to recover from injuries may be needed.

4 Attendence

Some pupils may have frequent medical appointments and/or may not cope with a full curriculum. Agree a way to keep in touch with pupils missing school for long periods (e.g. recording missed lessons). A part-time curriculum which includes some social interaction may be beneficial.

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We have a freephone adviceline open Tuesdays and Fridays 9.30am – 3.30pm which education professionals can contact for individual help and advice. We are also able to present (via Zoom) information at a school assembly or staff twilight session if you would like us to.

The Schools Toolkit has been re-written this year by Head Teachers, SENCOs and Support staff who are working in the current Education System and are up to date on all current policies and procedures. The original development of this toolkit was in collaboration with the HMSA and partly funded by grants from The D'Oyly Carte Charitable Trust and the Peter Harrison Foundation.

More resources:

Hypermobility syndromes Association: hypermobility.org

POTS UK: potsuk.org

Annabelles Challenge (vEDS): annabelleschallenge.org

Reasonable adjustments: educationhub.blog.gov.uk/2023/04/what-are-reasonable-adjustments-and-how-do-they-help-disabled-students-at-school

Council for disabled children: councilfordisabledchildren.org.uk

Supporting disabled children in Scotland: childrenshealthscotland.org/resource/supporting-disabled-children-young-people-and-their-families-guidance/

Supporting disabled children in Wales: gov.wales/supporting-learners-healthcare-needs-and-disabilities

Supporting disabled children in Northern Ireland: nidirect.gov.uk/articles/supporting-children-special-educational-needs

Supporting disabled children in England: gov.uk/children-with-special-educational-needs

Further reading:

Hypermobility Frequency in School Children: Relationship With Idiopathic Scoliosis, Age, Sex and Musculoskeletal Problems https://pmc.ncbi.nlm.nih.gov/articles/PMC6768787/

Prevalence of joint hypermobility in children and adolescents: A systematic review and meta-analysis https://pmc.ncbi.nlm.nih.gov/articles/PMC8019126/

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