CHRONIC PAIN PARTNERS

The EDS Back-to-School Advocacy Toolkit

Understanding 504 Plans, IEPs & School Accommodations for Students with Ehlers-Danlos Syndrome and HSD

A practical guide for parents, caregivers and school teams

Children with EDS/HSD may be bright, motivated students and still need meaningful support to access school safely and consistently. Pain, fatigue, joint instability, dysautonomia, headaches, gastrointestinal symptoms, sensory differences, neurodivergence and unpredictable flares can affect attendance, mobility, concentration, writing, testing and participation. The goal of accommodations is not to lower expectations. It is to remove disability-related barriers.

Core principle: Accommodations should follow the student's functional needs - not simply the name of the diagnosis.

For U.S. K-12 families • Parent-friendly • School-team ready

Educational disclaimer: This toolkit provides general educational information and is not legal advice, medical advice, or a substitute for individualized evaluation. Eligibility, services, and legal protections vary by individual circumstances, jurisdiction, school type, and funding. Private schools may have different obligations, eligibility criteria, and procedures than public schools. Families should consult their school or school district, qualified clinicians and, when needed, an appropriate special-education advocate or attorney.

1. Start Here: What School Teams Need to Understand About EDS/HSD

EDS and HSD can affect far more than joints. For some students, the school impact comes from a combination of pain, fatigue, instability, headaches, autonomic symptoms, gastrointestinal problems, sleep disruption, sensory differences, attention or executive-function challenges, and the physical effort required simply to get through a school day.

The invisible-disability problem

A student may look well and still be using substantial physical and cognitive energy to remain upright, move between classes, manage pain, take notes and concentrate. A good plan should respond to function, not require a child to repeatedly prove that symptoms are visible.

Common ways EDS/HSD can affect school

- **Attendance:** intermittent absences, late arrivals, appointments, hospitalizations or reduced stamina.
- **Mobility:** stairs, long hallways, crowded transitions, prolonged standing or carrying materials.
- **Writing:** hand pain, fatigue, instability or slower written output.
- **Concentration:** pain, fatigue, migraine, poor sleep or dysautonomia may reduce stamina and attention.
- **PE:** some activities may worsen instability, pain or injury risk; individualized modification may be needed.
- **Medical access:** water, electrolytes, snacks, medication, bathroom access, braces, compression or mobility devices.
- **Social participation:** repeated absences, disability or neurodivergence can affect friendships, belonging and school anxiety.

Variable disability matters

EDS/HSD and associated conditions can fluctuate. A student may walk independently one day and need mobility support another; complete a normal schedule one week and require rest or reduced workload during a flare the next. Plans work best when they anticipate variability rather than waiting for a crisis.

Words parents can use

"My child's needs are not identical every day. We would like the plan to describe what supports are available during symptom flares so teachers and our child do not have to renegotiate accommodations each time symptoms worsen."

2. 504 Plan or IEP?

Both 504 Plans and Individualized Education Programs (IEPs) can protect access to education, but they serve different purposes. A diagnosis of EDS does not automatically determine which plan a student needs. The question is how the student's disability affects school and what services are required.

	Section 504 Plan	IEP under IDEA
Main purpose	Provides aids, services and accommodations needed for equal access and FAPE under Section 504.	Provides special education and related services when a qualifying disability creates a need for specially designed instruction.
May fit when...	The student can access the general curriculum but needs disability-related supports such as attendance flexibility, mobility accommodations, extra time or assistive technology.	The disability adversely affects educational performance and the student needs special education, not accommodations alone.
Specially designed instruction	Not the defining feature.	Yes - central to IDEA eligibility.
Goals/progress	Does not use the IDEA IEP structure.	Includes measurable annual goals and progress reporting.

A student with a chronic health condition may qualify for an IEP under IDEA through a category called **Other Health Impairment (OHI)**. This may apply if the condition affects the student' s strength, energy or alertness, impacts their school performance, and means they need special education or related services.

When a 504 may not be enough

Consider requesting a special-education evaluation when accommodations alone are not allowing the student to make appropriate progress or participate meaningfully, or when the student may need specially designed instruction.

Important: A medical diagnosis by itself does not automatically create Section 504 services. Section 504 decisions are individualized. Federal guidance also says a medical diagnosis is not always required before a school can determine that a student has a disability under Section 504.

3. EDS/HSD Accommodation Menu

This is a discussion menu, not a one-size-fits-all checklist. Select only accommodations that match the student's actual functional needs and make them specific enough that everyone understands how they will work.

ATTENDANCE, FLARES & WORKLOAD

- Disability-related absences, late arrivals and early dismissals addressed without automatic academic or participation penalties.
- A written plan for obtaining instruction and materials during absences.
- Flexible deadlines following flares, procedures, hospitalizations or significant disability-related absences.
- Prioritized or reduced make-up work when completing every missed assignment would create an unreasonable backlog.
- Flexible test/rescheduling procedures after illness or absence.
- Consider shortened days, rest periods, homebound/remote options or other supports when individually appropriate and available.

MOBILITY, POSITIONING & PHYSICAL ACCESS

- Elevator access and reduced stair use.
- Extra transition time and/or permission to leave class early to avoid crowded hallways.
- Ability to change position, stand, stretch or take brief rest/movement breaks.
- Supportive or alternative seating when needed.
- Reduced need to carry heavy books/materials; duplicate books or digital materials when available.
- Use of prescribed braces, splints, compression garments and mobility devices.
- Accessible planning for assemblies, field trips, emergency drills and activities involving prolonged walking or standing.

WRITING, TESTING & CLASSROOM ACCESS

- Laptop/tablet, keyboarding, speech-to-text or assistive technology when handwriting is painful or fatiguing.
- Teacher-provided notes, slides, outlines or another note-taking support.
- Extended time when disability slows output or processing.
- Alternative ways to demonstrate knowledge when extensive handwriting is not essential to the learning objective.
- Reduced copying from the board and reduced repetitive written work when appropriate.
- Quiet or low-distraction testing location when individually needed.

4. Medical, POTS, PE & Sensory Supports

MEDICAL / AUTONOMIC SUPPORTS

- Immediate access to water and, when medically appropriate, electrolytes and snacks.
- Unrestricted bathroom access when medically necessary.
- Medication access consistent with school policy and the student's health plan.
- Access to the nurse or designated recovery/rest space without unnecessary delay.
- A clear response plan for dizziness, presyncope/syncope, migraine, acute pain, joint injury or other known episodes.
- Temperature/environment modifications when heat or cold significantly worsens symptoms.

A health plan and a 504 plan can do different jobs

A school health plan may describe medical management - medication, symptom response and nursing instructions. A 504 plan addresses the aids and services needed for equal educational access. Federal guidance notes that a health plan is not necessarily sufficient when a student needs Section 504 services.

PHYSICAL EDUCATION & ACTIVITY

- Individualized PE modification based on functional needs and appropriate clinical guidance.
- Alternatives to activities that create an identified safety or injury concern.
- Rest breaks and pacing rather than an all-or-nothing choice between full participation and sitting out.
- Modified expectations for timed running, repetitive impact, prolonged standing or other activities when disability-related limitations require it.
- Adaptive or alternative activities that preserve inclusion whenever possible.

SENSORY, NEURODIVERGENCE & SOCIAL PARTICIPATION

- Access to a quieter space, sensory breaks or environmental adjustments when individually needed.
- Advance notice of schedule changes when predictability supports functioning.
- Support for executive-function or organizational demands when evaluation shows a disability-related need.
- A designated trusted adult/check-in person when the student is navigating medical stress or repeated absences.
- Proactive planning for peer inclusion after prolonged absences and attention to disability-related bullying or isolation.

Avoid vague language

Instead of "extra time as needed," define when it applies and how much time is available. Specific language reduces conflict and makes plans easier to implement consistently.

5. Build a Flare-Day Plan Before the Flare

For a student with a variable condition, one of the most useful additions to a 504 or IEP is a written plan for days when symptoms increase.

Questions the team should answer

- How will the student signal that symptoms are worsening?
- Which accommodations become available or increase during a flare?
- Can the student rest, change position, hydrate, access medication or visit the nurse without unnecessary delay?
- How will missed instruction be provided?
- Which assignments are essential, which can be shortened, and which can be excused or replaced?
- How are quizzes/tests rescheduled?
- Who coordinates communication so the family is not contacting every teacher separately?
- What is the plan if symptoms persist for several days or attendance falls significantly?

Sample flare-day language

"Because the student's disability is episodic and symptoms can vary, approved accommodations may be used when disability-related symptoms increase. The student will be permitted to communicate a need for rest, hydration, positioning changes, nurse access, mobility support or other approved accommodations without being required to demonstrate visible signs of illness before using the accommodation. Following a significant flare or disability-related absence, the school team will prioritize essential work and establish reasonable revised deadlines."

Attendance deserves its own conversation

An accommodation that merely says "excused absences" may not solve the educational problem. Families should ask what happens after an absence: How does the student receive missed instruction? How quickly is make-up work due? Are tests stacked on return? Who helps prioritize the backlog?

Words parents can use

"We understand that attendance matters. Our concern is making sure disability-related absences do not create a cycle where returning to school becomes harder than the illness itself. Can we create a written re-entry and workload plan now, before the next flare?"

6. Preparing for a 504 or IEP Meeting

The strongest school plans connect a symptom to a functional barrier and then connect that barrier to a specific support.

What happens	School impact	Possible support to discuss
Hand pain / instability	Slow or painful handwriting	Keyboarding, speech-to-text, reduced copying, notes
Dysautonomia / fatigue	Standing, walking and attention are harder	Elevator, transition time, hydration, rest, seating
Pain / migraine flare	Missed class, reduced stamina	Flexible deadlines, reduced backlog, test rescheduling
Joint instability	PE/activity limitations	Individualized PE modification, pacing, alternatives
Sensory / neurodivergent needs	Overload or transition difficulty	Quiet space, sensory breaks, predictable routines

Bring useful information, not just a diagnosis

- A short description of diagnoses and, more importantly, how symptoms affect school.
- Relevant clinician, PT/OT or other professional recommendations when available.
- Attendance patterns, nurse visits, incomplete work, testing difficulties or other examples showing functional impact.
- A short list of the most important accommodations rather than an unprioritized wish list.
- The student's own perspective: what makes school harder and what helps.

Questions to ask before the meeting ends

- Who is responsible for communicating the plan to every teacher and substitute?
- How will we know whether each accommodation is being implemented?
- Who should the student contact when an accommodation is not available?
- When will the team reconvene if symptoms or attendance change?
- What data will we review to determine whether the plan is working?

Remember

A plan is only useful if the student can access it in real life. The goal is not to collect accommodations on paper. It is to create a predictable system that lets the student learn, participate and stay connected to school.

7. Trusted Resources & Federal Guidance

These resources are useful starting points for families and school teams. Federal guidance should be used for questions about U.S. legal requirements; EDS-specific resources help translate the condition into day-to-day school needs.

U.S. Department of Education - Section 504 FAPE FAQs

https://www.ed.gov/laws-and-policy/civil-rights-laws/disability-discrimination/frequently-asked-questions-section-504-free-appropriate-public-education-fape

Explains individualized Section 504 eligibility, evaluation and FAPE.

U.S. Department of Education - Hidden Disabilities & Section 504

https://www.ed.gov/laws-and-policy/individuals-disabilities/section-504/civil-rights-of-students-hidden-disabilities-and-section-504

Includes examples involving chronic illness, rest, testing, note-taking, mobility and modified PE.

IDEA Regulations - 34 CFR §300.8

https://sites.ed.gov/idea/regs/b/a/300.8

Defines IDEA disability categories, including Other Health Impairment, and the need for special education and related services.

Chronic Pain Partners - EDS K-12 School Accommodations

https://www.chronicpainpartners.com/parental-preparation-for-securing-accommodations-at-k-12-school-for-children-with-the-ehlers-danlos-syndromes/

EDS-specific school preparation and accommodation ideas.

Ehlers-Danlos Support UK - School Resources

https://theschooltoolkit.org/

Condition-specific educational materials for helping school staff understand EDS/HSD.

For families
You do not need to predict every difficult school day. You do need a team that understands the student's disability, listens when needs change, and has a plan for responding. Start with the barriers making school harder today, make the supports specific, and revisit the plan when needs change.

About Chronic Pain Partners

Chronic Pain Partners provides education, resources and community support for people living with Ehlers-Danlos syndromes and related conditions. Visit **ChronicPainPartners.com** for additional educational resources.

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