

Accommodations/Disability Resources for HSD and POTS

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Accommodations for students EDS/HSD

- Intended for children in primary school. Has a lot of handouts to share with teachers explaining what problems EDS may cause and how that may impact participation in school.
<https://theschooltoolkit.org>
- Intended for children in primary school: *Educator's and Parent's Guide to Children with EDS*. Includes suggested school modifications and accommodations. <https://www.ehlers-danlos.com/wp-content/uploads/2016/06/Educator-Parent-Guide-2016.pdf>
- College: Includes discussion of university housing, absence, handwriting, rest periods, etc.:
<https://www.quora.com/What-accommodations-should-I-get-at-university-for-Ehlers-danlos-syndrome>

POTS

- Accommodations for POTS for college students:
<https://www.standinguptopots.org/livingwithpots/school>
- The Dysautonomia Support has handbooks about school and college accommodations for dysautonomia: <https://www.dysautonomiasupport.org/handbooks/>
- Accommodations for children and teens with both dysautonomia and ME/CFS: (and fact sheet)
 - Rowe PC, Underhill RA, Friedman KJ, Gurwitt A, Medow MS, Schwartz MS, et al. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. *Front Pediatr.* 2017;5:121.

MCAS

School/college MCAS information booklets: <https://www.mastcellaction.org/resources>

Work accommodations

- EDS/POTS/Fibromyalgia: Job Accommodation Network. Look up EDS, POTS and Fibromyalgia.
<https://askjan.org>
 - <https://askjan.org/disabilities/Ehlers-Danlos-Syndrome.cfm>
 - <https://askjan.org/disabilities/Postural-Orthostatic-Tachycardia-Syndrome-POTS.cfm>
 - <https://askjan.org/disabilities/Fibromyalgia.cfm>. While fibromyalgia is a different condition, many of the accommodations address issues like fatigue, brain fog, and chemical sensitivity that are not included in the EDS content.
- POTS/EDS: Great specific suggestions for dysautonomia, but also relevant to HSD: The Dysautonomia Support Network - <https://www.dysautonomiasupport.org/handbooks/>

- Booklet about MCAS for disability officers: <https://www.mastcellaction.org/resources>
- [NASEM Report on HSD/EDS and disability](#). The National Academy of Science, Engineering and Medicine report that is a comprehensive overview of functional limitations that may lead to disability people with HSD/EDS. It also lists many potential accommodations. The tables at the end of chapter 5 might be particularly helpful.
 - Annex Table 5-3 identifies common physical manifestations
 - Annex Table 5-4 identifies common neurological manifestations
 - Annex Table 5-5 identifies common cardiovascular and hematologic manifestations
 - Annex Table 5-6 identifies common respiratory manifestations
 - Annex Table 5-7 identifies common immune manifestations, including MCAS
 - Annex Table 5-8 identifies common gastrointestinal manifestations
 - Annex Table 5-9 identifies common skin/cutaneous manifestations
 - Annex Table 5-10 identifies common genitourinary manifestations
 - Annex Table 5-11 identifies common vision, hearing and speech issues
 - Annex Table 5-12 identifies common cognitive and neuropsychiatric consequences
 - Annex Table 5-13 identifies common problems with global function. This table includes global symptoms of pain and fatigue
 - **Annex Table 5-14 identifies common functional implications: e.g., reasons for difficulty sitting, standing, walking, fine motor control, hearing, speaking, cognitive function, concentration, ability to persist in work activities, interact with other people, adapt or manage self**
- An excellent explanation about how to apply for jobs if you require accommodations, such as what to share, when to share, what they can require: <https://careered.stanford.edu/students-postdocs/diversity-equity-inclusion-belonging-resources/accommodations-during-hiring>

Disability

- The NASEM Report summary statements starting at page 158 may be useful to identify why a person with HSD/POTS/MCAS might have difficulty working. It's about much more than just pain. These are also listed later in this document.
- Some general information about disability and the process of applying for disability in the US (I selected this website from many as it isn't trying to sell legal services): <https://www.eds.clinic/articles/guide-to-disability-claims-for-ehlers-danlos-syndrome-patients>

The Dysautonomia Support has a series of excellent handbooks about accommodations for dysautonomia. Many of these very specific suggestions could be helpful for HSD without POTS. <https://www.dysautonomiasupport.org/handbooks/>

- [Thriving with Assistive Technology Handbook](#)
- [Thriving in School: Navigating K-12 Education with Dysautonomia Handbook](#)
- [Thriving in College: Navigating College with Dysautonomia](#)
- [Thriving at Work: Navigating Workplace Accommodations & Employment with Dysautonomia](#)

NASEM report, conclusions in Chapter 5

Citation: National Academies of Sciences, Engineering, and Medicine. 2022. Selected Heritable Disorders of Connective Tissue and Disability. Washington, DC: The National Academies Press. <https://doi.org/10.17226/26431>.

The following statements in the NASEM report can support requests for accommodations or disability:

FINDINGS AND CONCLUSIONS

Findings

- 5-1. The number, type, and severity of the physical and mental secondary impairments experienced by an individual with a heritable disorder of connective tissue (HDCT) drive the person's functioning and potential disability.
- 5-2. Environmental factors (e.g., temperature extremes, noise, vibration, atmospheric conditions, inhaled or skin irritants) can have significant adverse effects on function for some individuals with HDCTs.
- 5-3. Both physical and mental conditions can precipitate or exacerbate decrements in physical and mental functioning in individuals with HDCTs.
- 5-4. Chronic pain, chronic fatigue, and mild cognitive impairment are some of the most common and potentially disabling manifestations of the Ehlers-Danlos syndromes (EDS), especially hypermobile EDS (hEDS), hypermobility spectrum disorders (HSD), and Marfan syndrome (MFS).
- 5-5. A complex relationship exists among pain, fatigue, postural orthostatic tachycardia syndrome, and mast cell activation disease.
- 5-6. Pain can interfere with all types of physical activities that may be entailed in work or school, including sedentary activities. Pain also has an effect on cognitive functioning.
- 5-7. Fatigue associated with EDS/HSD and MFS can result in a number of physical and mental functional impairments that affect daily activities, including participation in work and physical activities.
- 5-8. Mild cognitive impairment can adversely affect participation in school, work, and social activities.
- 5-9. A challenge in assessment of functioning is capturing the full effect of individuals' impairments on their daily activities, including at work and in school. This is particularly true when a person has multiple impairments.
- 5-10. Numerous validated performance-based and self-reported measures are available for assessing physical and mental functioning, including several that can be used to perform an integrated assessment of an individual's overall physical and mental functioning.
- 5-11. Performance of a specific physical activity rarely if ever occurs independently of other physical activities.
- 5-12. Performance at work and in school, where physical, cognitive, and emotional stressors are often greater than in the testing environment, may be affected in ways not observed during testing.
- 5-13. Physical activity guidelines and restrictions for individuals with HDCTs need to be tailored to the specific person.
- 5-14. General physical activity guidelines exist for people with MFS and related disorders, such as avoidance of intense isometric exercise, contact sports that can lead to blows to the head, activities that involve rapid acceleration and deceleration over short distances (sprinting) or rapid changes in pressure (e.g., scuba diving), and exercise to the point of exhaustion.
- 5-15. Depending on a person's underlying impairment(s), assistive technologies and relevant accommodations can improve physical and mental functioning in some cases.
- 5-16. Some of the listings in SSA's Listing of Impairments—Adult Listings include severity criteria for some of the secondary impairments that may be experienced by individuals with HDCTs such as MFS, EDS, and related disorders.
- 5-17. Individuals with HDCTs may experience significant variability in their physical and/or mental secondary impairments from day to day or even within a single day. This variability is often unpredictable and may limit the ability to sustain gainful employment.