

Support for Employers

You can find all of this information and links to downloadable resources on our website.



This toolkit has been designed to give educational staff practical guidance for employers.

Audience: Employers, Employees, HR Professionals and other staff.

How to use this guide

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

This resource is designed to help schools identify common reasonable adjustments, and understand the outcomes those adjustments may support. Not every adjustment will be appropriate for every person. Support should always be individualised and developed in partnership with the employee and relevant healthcare professionals.

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

EDS and HSD are complex conditions affecting many different parts and systems of the body at once. Despite this, they are often invisible. In addition to problems associated with hypermobility, those affected may also have skin which damages easily, bruises and is slow to heal, or alternatively can be thick and velvety. Different symptoms and their severity vary considerably from person to person and are unique, even in the same type of EDS and within the same family. Some other conditions seem to be more common in people compared to the general population but we can't say for certain that they are linked.

Individuals with HSD or some types of EDS can experience symptoms related to the abnormal function of the autonomic (involuntary or automatic) nervous system. The term autonomic dysfunction is used. It is not yet clear how HSD or EDS and autonomic dysfunction are linked. In some people with autonomic dysfunction, symptoms come on when they are upright and are mostly relieved by lying down. This is called orthostatic intolerance or postural orthostatic intolerance (PoTS). Symptoms of PoTS include palpitations (a sensation of your heart pounding in your chest), lightheadedness or dizziness, sweating, fainting, fatigue and headaches. They can also affect the gut (where nausea, diarrhoea, constipation, bloating, abdominal pain and vomiting can be experienced), concentration and vision (excessive glare, blurred or tunnel vision).

There is evidence of an association between hypermobility and anxiety, and hypermobility and neurodiversity, but the relationship is not yet fully understood.

Key facts

- EDS and HSD are lifelong conditions that affect connective tissue throughout the body.
- Hypermobility is quite common in the general population.
- Symptoms vary significantly between people.
- Many people look well despite experiencing significant symptoms and may cause problems for employees at work and these are likely to occur before a diagnosis has been given.
- Particularly severe symptoms may affect a person's 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 work and attendance.

- Reasonable adjustments can help employees participate fully in the workplace.
- Employees may require support from multiple professionals and services.
- People with EDS or HSD often fidget and need to move about

What employers need to know

Most employers do not need specialist medical knowledge.

The most important role of employers is to:

- recognise the barriers to the employee working at full capacity
- understand how symptoms may affect work
- make appropriate adjustments
- work collaboratively with the employee

It can be tempting to dismiss reports of pain from an employee 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 employee.

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 employee to do more. Various techniques can be used.

Clothing

Some employees may need some flexibility in what they are allowed to wear for work if there is a dress policy. For example, braces worn to stabilise joints may be difficult to fit under trousers or shirts; boots rather than shoes may be needed to support unstable ankle joints. Some people 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.

What are my obligations as an Employer?

- The Flexible Working (Amendment) Regulations came into force on 6th April 2024 and these require employers to consider flexible working requests from day one of employment, so it makes sense to incorporate these into your recruitment strategies from the outset.
- Ensure your employees know their medical conditions are private and confidential and that you will not share your details with anyone who does not need to know.
- Employees should be made aware they have a right to request reasonable adjustments to allow them to continue in a role

What else can I do to support employees?

- Creating a more supportive workplace can result in greater productivity, morale, retention, as well as reduced sickness absence and 'presenteeism'.
- Remember that employees have the right to confidentiality and may want the adjustments to be made discreetly.

- It is essential that employers and managers learn more about life with musculoskeletal (MSK) conditions and foster a workplace where employees feel they can discuss their health openly with their employer.
- Small changes can have a big difference. This can include employers offering more flexible working hours, longer or more frequent breaks throughout the day, and increased availability of specialised equipment such as standing desks and ergonomic chairs.
- The Government's Access to Work Scheme can provide help where expensive adjustments are necessary to allow employees to remain at work and you may be eligible for a grant to cover these. The scheme can also help with mental health support.
- Often, employees just need understanding and reassurance that they are not alone and that their symptoms will get better with support. It can be helpful to signpost employees to charities like ours, EDS UK, or local services, where available. We can then help them improve their mental health or feelings of isolation, and signpost them to local resources and support.

What are reasonable adjustments?

The employee is the expert in how your condition affects them and will know their job well enough to judge what reasonable adjustments could make a difference to how they manage work.

Reasonable adjustments might include specialist equipment, adjustments to the role, or a change to work patterns that will remove some of the problems they face at work. However, we understand that it can also be hard to know exactly what is available or what could make a difference to them.

Some examples of reasonable adjustments in the workplace are shared within the Equality and Human Rights [EHRC website](#), with videos of those who have applied for adjustments. These may help you consider their situation and how they could apply. Working together with your employee or workplace support can help you to help them to identify what would work and how it could be implemented.

Listed below are some questions to consider if someone's condition is impacting on their capacity to work:

- What work tasks do you feel need to be reviewed, adapted, or removed to make their role manageable?
- Can you swap some tasks and find alternative tasks they can do instead?
- Is there specialist equipment, computer software or training that may help make their job easier?
- Consider hours and location; would they benefit from working from home, flexible or reduced hours, shorter working week, or longer breaks between work days?
- Remember to consider those periods when conditions fluctuate or flare, they start new treatment, or experience a setback. They may need **additional** support to help continue to work, **over and above** what you have already agreed during the times when their condition is stable.
- Do you know if you need a health and safety review to ensure they are working safely?
- Is travel to and from work part of the problem, are there times when they struggle to drive safely, or travel on public transport?
- Consider who can help you work through this – manager, HR staff, job centre staff, union rep, occupational therapist, employment adviser, local advice service?
- Would they benefit from an Occupational Health, Ergonomic or Access to Work assessment to help identify what they need?

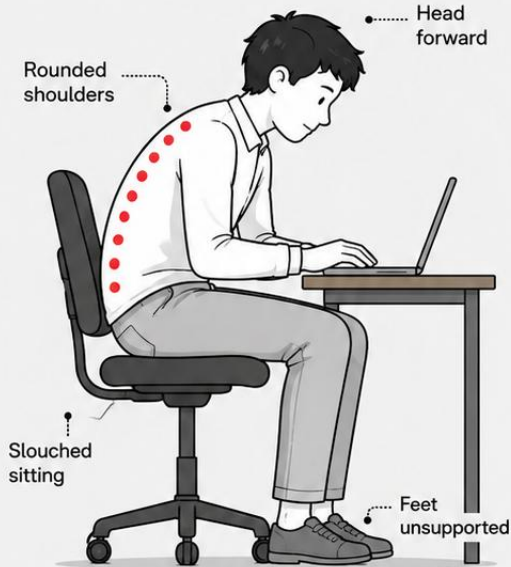
Steps for supporting employees

1. **Engage in Dialogue:** Discuss with the employee what support they need, avoiding assumptions, as advised in the Acas guidance on making and handling requests.
2. **Make Reasonable Adjustments:** These can include altering working hours, providing specialized software, or rearranging office space.
3. **Use Access to Work:** Encourage employees to apply for AtW grants to cover costs exceeding reasonable adjustments.
4. **Create an Inclusive Culture:** Train staff and managers on disability awareness and neurodiversity.

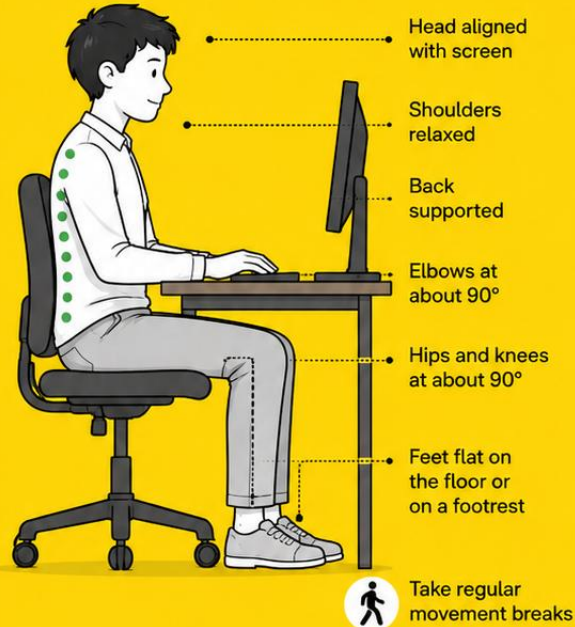
Good Posture for Work

Helping hypermobile adults stay comfortable and reduce pain.

✗ AVOID



✓ BETTER POSTURE



SUPPORT

Use a chair that supports your back and adjust it to fit you.



FEET

Keep feet flat on the floor or on a footrest.



TASKS

Keep your screen at eye level and take regular breaks.



MOVE

Stand, stretch and move regularly to prevent stiffness.



REMEMBER: There is no perfect posture.

The best posture is your next posture. Change position regularly and keep moving.



For more resources, case studies and downloadable resources go to ehlers-danlos.uk/support-for-professionals-and-employers/employers-toolkit/

Signs and symptoms



EDSUK

Common symptoms

Severe tiredness

Neck instability

Difficulty regulating blood pressure

Persistent 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)
Registered Company No. 8924646. Registered Address: EDS UK, International House, 66 Lavender Hill, London, SW11 5RQ

ehlers-danlos.uk

TOP TIPS



EDSUK

for an EDS and HSD friendly workplace

The Ehlers-Danlos syndromes (EDS) are a group of genetic connective tissue disorders with symptoms affecting the whole body. Hypermobility spectrum disorder (HSD) has similar symptoms to the most common type of EDS, the hypermobile type. Those affected by EDS or HSD may face challenges to their physical and mental health.

1

Adapt

People with EDS or HSD have symptoms which vary greatly from day to day and often have to adapt their work plans, environment and aspirations due to their condition.



2

Ergonomics

People with EDS or HSD may find physical tasks or long shifts difficult.

Simple physical adaptations such as an ergonomic workspace setup and the use of assistive technology can help overcome many barriers in the workplace.



Be flexible

A flexible approach which allows planning, pacing and varying hours or breaks according to symptoms.

These simple things can help people with EDS or HSD stay in work for longer.



3

4

Law

Employers are required by law to make reasonable adjustments to prevent people with a disability or physical or mental health condition from being disadvantaged. They may be able to get help from the Access to Work scheme: gov.uk/access-to-work



Call the Adviceline **0800 907 8518** or email adviceline@ehlers-danlos.uk

Follow us on      @ehlersdanlosuk  @ehlersdanlossupportuk

Visit us at ehlers-danlos.uk

The Ehlers-Danlos Support UK is a charity registered in England and Wales (No. 1157027) and Scotland (SC046712) Registered Company No. 8924646. Registered Address: EDS UK, International House, 66 Lavender Hill, London, SW11 5RQ

EDS UK offers an adviceline which is available to employers and employees.

ehlers-danlos.uk

Adviceline 0800 907 8518

EDSUK©



More resources:

- Equality Act 2010: gov.uk/guidance/equality-act-2010-guidance
- Reasonable adjustments for workers with disabilities or health conditions: gov.uk/reasonable-adjustments-for-disabled-workers
- ACAS: acas.org.uk/reasonable-adjustments
- ARTHRITIS uk): arthritis-uk.org/information-and-support/understanding-arthritis/conditions/joint-hypermobility/
- EvenBreak - job board for disabled people: www.evenbreak.com
- Business Disability Forum for employers: businessdisabilityforum.org.uk
- Abilitynet: abilitynet.org.uk
- Good Employment Charter: gmgoodemploymentcharter.co.uk/disability-guide-for-employers
- At.Train: attrain.com
- NHS support for employers: www.nhshealthatwork.co.uk/support-for-business.asp
- Access to work: <https://www.gov.uk/access-to-work>

Further reading:

- The Impact of Pain on Everyday Activities of People With Hypermobility Spectrum Disorders or Hypermobility Ehlers Danlos Syndrome <https://pmc.ncbi.nlm.nih.gov/articles/PMC11822559/>
- Understanding the psychosocial impact of Joint Hypermobility Syndrome and Ehlers-Danlos Syndrome Hypermobility Type: A qualitative interview study https://orca.cardiff.ac.uk/id/eprint/158216/1/Bennett%20et%20al_%20Interview%20Study%20ACCEPTED.pdf

References:

- Adib, N., Davies, K., Grahame, R., Woo, P., & Murray K.J. (2005) Joint hypermobility syndrome in childhood. A not so benign multisystem disorder? *Rheumatology*, 44 (6), pp. 744–750,
- Baeza-Velasco, C., Cohen, D., Hamonet, C., Vlamynck, E., Diaz, L., Cravero, C., & Guinchat, V. (2018). Autism, Joint Hypermobility-Related Disorders and Pain. *Frontiers in psychiatry*, 9, 656.
- Demmler, J.C., Atkinson, M.D., Reinhold EJ, et al. (2019). Diagnosed prevalence of Ehlers-Danlos syndrome and hypermobility spectrum disorder in Wales, UK: a national electronic cohort study and case-control comparison. *BMJ Open*, 9.
- Eccles, J.A., Beacher, F.D., Gray, M.A., Jones, C.L., Minati, L., Harrison, N.A., & Critchley, H.D. (2012). Brain structure and joint hypermobility: relevance to the expression of psychiatric symptoms. *The British journal of psychiatry: the journal of mental science*, 200 (6), pp. 508–509.
- Eccles, J., Iodice, V., Dowell, N, et al. (2014). Joint hypermobility and autonomic hyperactivity: relevance to neurodevelopmental disorders. *Journal of Neurology, Neurosurgery & Psychiatry*, 85:e3.

This toolkit has been put together by a number of professionals and patient experts and we would like to thank everyone who has been part of putting this resource together.