

Making life work with EDS

Workplace Fact Sheet: Supporting Employees with Ehlers-Danlos Syndrome (EDS)

Ehlers-Danlos Syndrome (EDS) is a group of genetic connective tissue disorders characterised by joint hypermobility, skin fragility, and tissue elasticity. Individuals with EDS may have one or multiple types of EDS. They experience chronic pain, fatigue, and a range of other symptoms along with gastrointestinal and nervous system issues that can impact their daily lives and work performance.

What is Ehlers-Danlos Syndrome (EDS)?

Connective Tissue Fragility



EDS patients have fragile connective tissues, which may predispose them to injuries, dislocations, & vascular complications.

Chronic Pain Management



Chronic pain is common in EDS patients along with "flare ups" & fatigue requiring tailored pain management strategies.

Multi-System Involvement



EDS can affect multiple organ systems, including gastrointestinal & autonomic nervous system issues, requiring specialist intervention.

Variable Symptoms



EDS can cause complex & variable symptoms that change, from mild to severe, including fatigue, pain, gastrointestinal & cardiovascular issues.

Managing the symptoms of EDS requires a comprehensive approach that acknowledges the complex nature of the condition and the potential impact it may have on employees' ability to perform tasks effectively. Employers should be aware of these challenges and be proactive in providing appropriate accommodations and support to employees with EDS.

DID YOU KNOW?

People with Ehlers Danlos Syndrome are referred to as Zebras. This comes from the saying often used in medicine, "If you hear hoofbeats, think horses, not zebras."



Some famous people with Ehlers Danlos Syndrome include Billie Eilish, Selma Blair, Sia, Lena Dunham and Jameela Jamil.



Some of the benefits to Employers of Supporting Employees with EDS:

Retention of Knowledge & Skills



Supporting employees with chronic conditions like EDS demonstrates commitment to diversity & inclusion, which can enhance employee loyalty & retention.

Increased Productivity



By accommodating the needs of employees with EDS, employers can help them manage their condition more effectively, leading to improved productivity & job satisfaction.

Positive Work Environment



Creating a supportive and inclusive work environment benefits all employees, fostering a culture of empathy, respect, and teamwork.

Social & Environmental Contribution



Employment of individuals with EDS provides opportunities to contribute & do something within their control, which is positive for society, the economy & personal wellbeing.

They are often hard working and dedicated employees despite physical challenges faced in daily life.

How you can support Employees with EDS?

Flexible Work Arrangements



Flexible work hours & remote work options



Flexibility in job tasks & responsibilities

Accessible Environment



Accessible and ergonomic workplace with provisions



Wheelchair & disability accessible bathroom & facilities

Open Communication



Foster open communication where employees feel comfortable discussing EDS needs & concerns



Maintain employee confidentiality & obtain guidance on communicating employee accommodations to clients & colleagues

Establish Boundaries



Encourage employees to set & communicate boundaries, limitations & accommodations



Avoid anticipating limitations or limit opportunity to contribute

Educational Resources



Proactively educate yourself about EDS & share resources



Celebrate awareness and advocacy days

Supportive Policies



Implement policies that prioritise the health and well-being



Support minor changes to practices & norms needed for symptom management

Supportive Resources



Offer adjustable ergonomic aids



Provide Employee Assistance Programs (EAP) or counselling services for support

PRACTICAL EXAMPLES

- Change in work hours (spread of hours) to accommodate fluctuating symptoms & medical appointments.
- Frequent breaks to enable pacing.
- Reduction of travel requirements replaced with virtual.

- Provide a lay down/rest area for fatigue management in the workplace and/or work from home arrangements.
- Space for physical movement activities (stretching & physiotherapy exercises) to maintain movement.
- Adjustable desks and supportive seating.

- Record a GP emergency contact for medical episodes.
- Obtain their guidance on accommodations & protocols to safely support in-office and virtual working in consultation with the employee.
- Schedule regular check-ins with employees to discuss their needs, accommodations, and any adjustments that may be necessary to support their continued success in the workplace.
- Employee Assistance Programs (EAPs) can provide guidance & support on communicating EDS accommodations to clients & colleagues.

- Establish boundaries i.e. length of workshops limited to 90 minute blocks.
- Setting of standard meeting times to avoid symptom flare up times.

Share resources & support groups for EDS patients & carers:

- <https://www.ehlersdanlosaus.com/>
- <https://www.ehlers-danlos.org/>
- <https://www.stuffthatworks.health/>
- Celebrate Awareness & advocacy days:
- Rare Disability Awareness day (Last day of February)
- Ehlers Danlos day (May 19th)
- Chronic Disease Awareness Day (July 10th)
- Invisible Disabilities Week (Approx. Oct 20th)

- Exception to policy to supply medical certificates to reduce financial burden.
- Able to bring food and drinks into meetings.
- Able to stand up and stretch in settings where attendees are expected to remain seated and how to normalise this for others.

- EAP Access for employees, colleagues and managers.
- Adjustable seating, footrests, ergonomic keyboards/mouse rests, Requesting team flexibility to support backfill for appointments to address acute health issues and work around acute symptoms.

Refer to <https://www.fairwork.gov.au/find-help-for/employees-with-disability>. It is imperative for employers to be willing to provide an accessible work environment and reasonable accommodations, such as assistive devices or modified job tasks, flexible work arrangements to help employees manage their condition effectively. Employees may prefer to source their own assistive devices for the workplace, which should be respected wherever possible.

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