D&A Diversity and Ability

NADP Annual Conference 2023
What is Reasonable?

What the Realities of Ehlers Danlos Syndrome Teach Us About Access and Adjustments

Session Overview

- Introductions
- What is Ehlers Danlos Syndrome?
- How does the Social Model of Disability apply to EDS?
- What barriers do those with EDS face?
- Adjustments

D&A Diversity and Ability

CELEBRATE DIFFERENCE

Diversity and Ability

- We're a **social enterprise** led **by and for disabled people**
- We champion **intersectional neurodiversity** and **disability inclusion**
- **85%** of our team identify as disabled or neurodiverse
- **100%** of our clients would reuse our services

Training

Consultancy

1-2-1 Support

Campaigning

Introductions

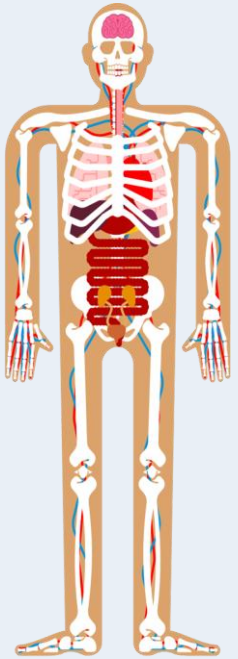
Charlotte Twinley (she / they)
Accessibility and Inclusion Specialist

- Diagnosed with hypermobile Ehlers Danlos Syndrome (hEDS) in 2013, at 15 years old
- Experiences challenges with joints, digestive system, chronic pain, fatigue, brain fog and processing
- Started working at Diversity and Ability (D&A) in April 2022, after struggling with workplace barriers

What is Ehlers Danlos Syndrome?

What is Ehlers Danlos Syndrome?

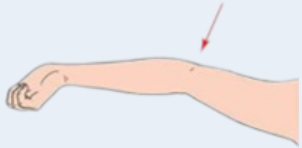
- The **Ehlers Danlos Syndromes** (EDS) are a group of connective tissue disorders, caused by a genetic mutation
- There are **13** different types of EDS, including:
  - Classical EDS
  - Hypermobile EDS
  - Vascular EDS
  - Kyphoscoliotic EDS
- Connective tissue is found **everywhere** in the body, which means there are many ways it can affect someone



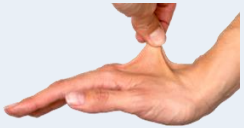
“If you can’t connect the issues, think connective tissues!”

How do symptoms present?

Everyone is different!



Joint hypermobility



Stretchy skin

Easy bruising

Digestive problems

Chronic fatigue

Brain fog

Diagnosis

- Diagnosis can often take **years**
- Lack of awareness can lead to **misdiagnosis** and lengthy doctors appointments and hospital tests
- Most tests often come back **‘clear’**
- Medical students are typically taught:

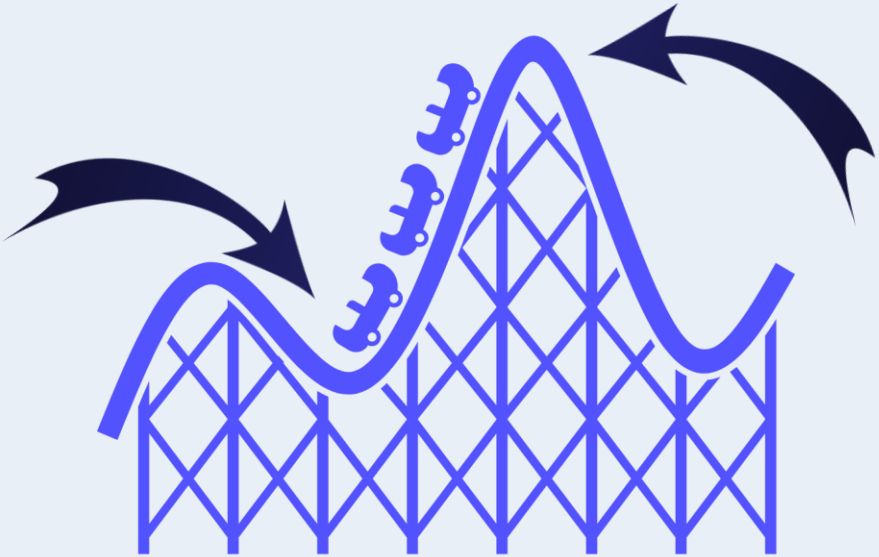
“When you hear hooves, think horses - not zebras”

- But this can lead to many conditions **not** being diagnosed

EDS is an example of a ‘Dynamic Disability’:

Dynamic Disabilities can be a bit like a rollercoaster.

On some days, symptoms will be much **worse** and fatigue will be low.



On other days, symptoms will be well-controlled and energy levels will be **good**.

What does this mean?

Dynamic Disabilities have no particular **‘look’**

For example:

One day, a person might really be **struggling** with their pain and fatigue,

but feel much **better** the **next** day - and vice versa and everything in-between!

This **doesn’t** mean that they’re magically better, or that they were exaggerating their symptoms.

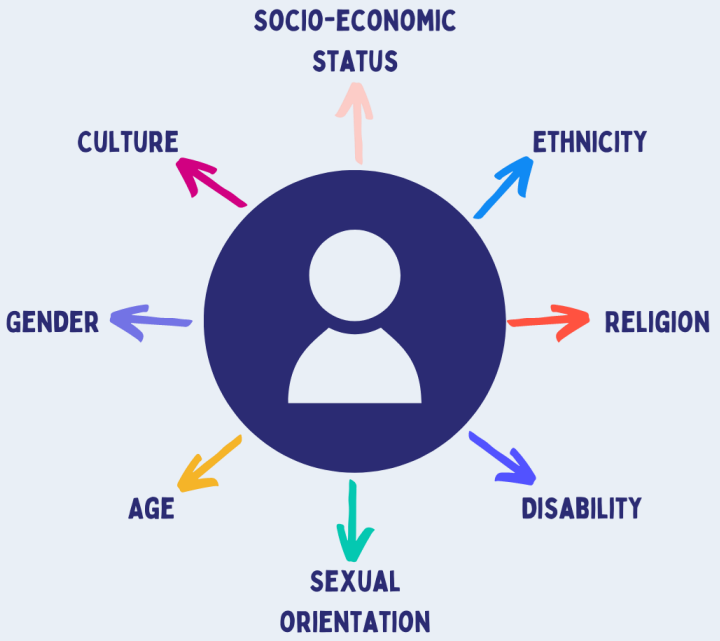
Intersection between EDS and mental health

- **Strong link** between EDS and mental health challenges
  - Particularly with depression and anxiety
  - Many report challenges with eating disorders, addiction and OCD

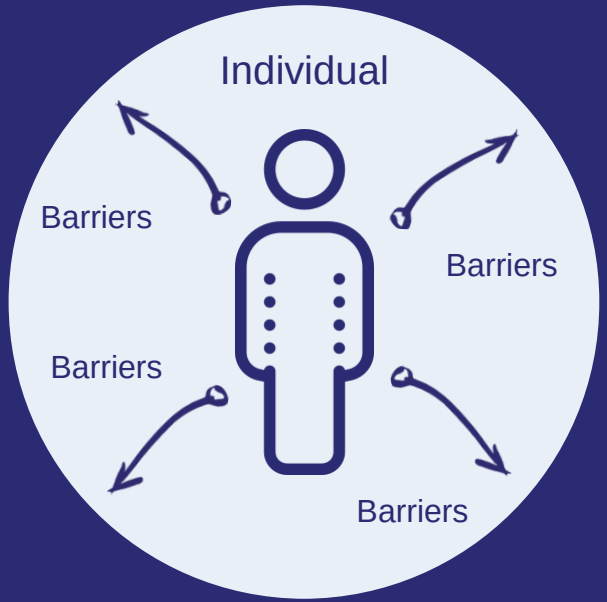
- **Contributing** factors can include:
  - Chronic pain
  - Chronic emotional stress
  - Increased isolation due to deteriorating health
  - Side effects of medications

Chronic health: intersectionality

- An individual's chronic health will be affected by other facets of their identity
- These are often intertwined and impact on one and other
- Must consider all of these intersecting attributes when supporting someone



How does the Social Model of Disability apply to EDS?



Medical Model creating barriers to learning participation

- Medical Model implies that the problem is with the student, and not strict educational guidelines
- Example:
  - To support my circulation, I sometimes wore specific gloves in classes to limit my pain
  - Teachers would tell me off as it didn't align with the uniform
  - I wasn't able to concentrate in class due to the pain I was experiencing with my circulation
  - This hindered my participation in classes

Importance of Social Model with EDS

- Implementing **adjustments** to help remove barriers that students face will **support** their learning participation
- Education can often be **disabling** due to its:
  - strict lesson timings and plans
  - uniforms
  - lack of ergonomic equipment
  - pressure
  - and more!
- When a student comes across a barrier, it's **not** their fault

Going one step further with the Celebratory Model

Everyone is valued as unique individuals who have their own brilliant skill set

- Making adjustments **proactively** to enable people to reach their full potential
- Creates a sense of belonging
- Everyone can thrive!

Celebratory Model with EDS

- Focusing on **how** we can enable a person to thrive
- What barriers can we **proactively** remove to reduce **impact** of barriers
- No cure, only **management**
- Removing barriers won't cure my pain and fatigue, but will **enable** me to do my work

What barriers do those with EDS face?

Things to remember:

- Everyone will have **different** barriers
- Impact of **comorbidities** (such as PoTS, ME, Fibromyalgia etc)
- Consider link between EDS and **Neurodiversity**
- Not everyone will have received a **diagnosis**
- Not all barriers are **visible**!

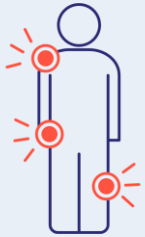
Potential barriers with EDS in Education

Chronic Pain	→	No Ergonomic Equipment
Fatigue and Anxiety	→	Processing
Brain Fog	→	Memory and Concentration
Medical Appointments	→	Missing Important Info

Impacts of barriers in education

Burnout / exhaustion

Isolation



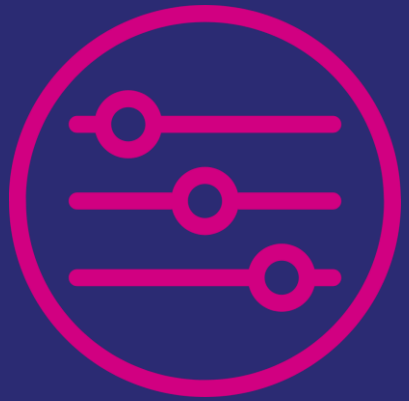
Chronic Pain

Absenteeism

Anxiety

Leaving

Adjustments



Removing barriers to support students with EDS

Flexible studying

Ergonomic equipment

Online classes

Assistive technology

Extra time for processing

PA / note taking support

An example of an adjustment that helped me

- I can't write too much with my hands due to **pain** and **dislocations** in my fingers and wrists
- **Typing** was much easier for me
- I was allowed to **type notes** on an iPad / laptop in lessons
- With a doctor's note for the exam boards, I could type **during exams** as well

*note: without the doctor's note and diagnosis,
I may not have been allowed to by exam boards

Supporting someone with a Chronic Condition

There are some key things you can do to help **support someone** with a Chronic Condition, such as:

- Allowing time for **medical appointments** and **medication**
- Being understanding and allowing them to **rest** when needed
- Actively ask **how** you can help
- **Include** them in social situations to avoid isolation
- Be **flexible** and allow them to recharge when needed
- Know that there is **diversity** in Disabilities and Chronic Conditions

What does EDS teach us about access and adjustments?

- **Not** a **‘one size fits all’** solution
- Everyone will have **different** experiences, challenges and barriers
- EDS affects everyone in **different** ways, just as we are all different in our own right
- Adjustments and access to supports needs to be done **holistically**
- Think about **intersectional** impacts and other diagnoses

CELEBRATE DIFFERENCE

D&A Diversity and Ability

Social Media

- diversity-and-ability
- @dnamatters
- @DandA_inclusion
- diversity_and_ability

Contact Us

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- https://diversityandability.com/