




## Living with ADHD and EDS / HSD

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2<sup>nd</sup> November 2019


THE EHLERS-DANLOS SOCIETY CONFERENCE  
**EDINBURGH 2019**



## Who am I & Why am I here?

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- Consultant Psychiatrist in London (NHS and private practice)
- National Expert in Adult ADHD
- Training Programme Director for UKAAN



**“I am starting to suspect that a subset of patients actually have ADHD secondary to EDS, with important implications for treatment”**

- Five years ago, I noticed that a disproportionate number of my patients with ADHD had a history of hypermobility
  - Self-education and literature search (very little found on link!)
  - Informal screening my patients with ADHD and Anxiety for EDS / JHS
  - Building a network of professionals



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*Connective tissue problems and attention deficit and hyperactivity*

**Carolina Baeza-Velasco, Myriam Soussana & Amaria Baghdadli**



**Published 2018**

## Linking ADHD and EDS /HSD (1)

- Psychological dysfunction is common in EDS / HSD
  - Associations found with anxiety, depression, sleep problems and neurodevelopmental issues like Dyspraxia (DCD)
  - Numerous references in the literature to 'Attentional difficulties', less refer specifically to ADHD
- 2001 Turkish study (Tanner et al 2011)
  - 54 children with ADHD studied
  - **31.5% diagnosed with Joint Hypermobility Syndrome**
- 2014 paper by Jessica Eccles
  - High rates of hypermobility and symptoms of autonomic dysfunction in adults with neurodevelopmental diagnoses including ADHD



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## Linking ADHD and EDS /HSD (2)

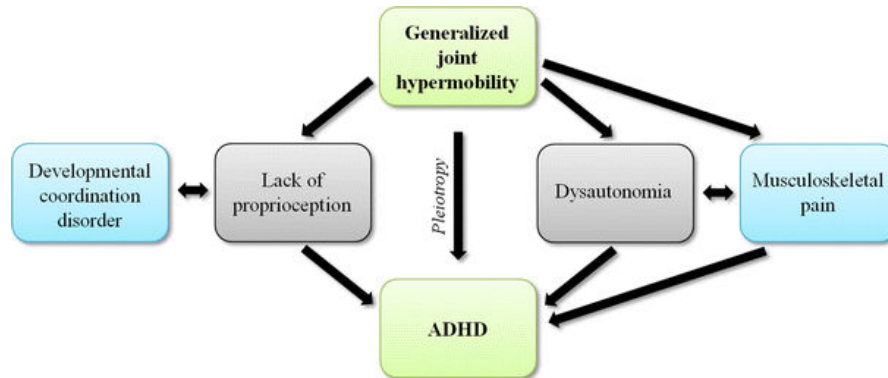
Potential explanations for the association:

- 1. Dysautonomia** (disordered autonomic function)
  - Association with orthostatic intolerance
- 2. Impaired proprioception**, impacting co-ordination
  - Diversion of attention onto motor activity
- 3. Chronic pain**, diverting energy and attention
- 4. via Convergence Insufficiency** – a common eye-teaming vision disorder in which eyes tend to drift outwards when reading. Compensatory efforts absorb attention
- 5. Shared underlying genetic / environmental risk**



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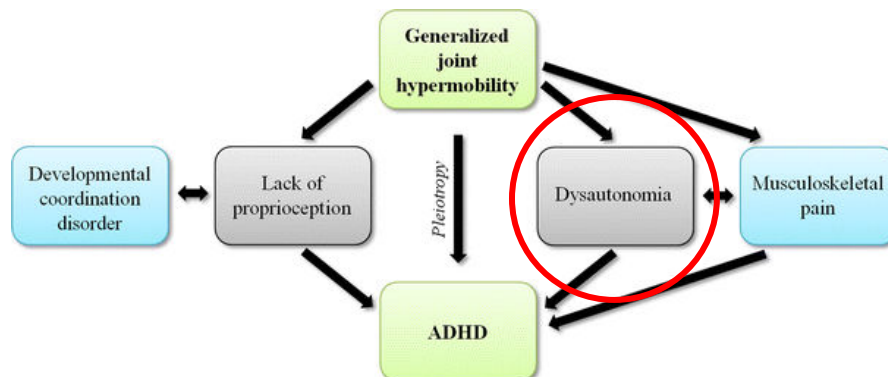


Baeza-Velasco, Sinibaldi, Castori 2018



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## Linking ADHD and EDS /HSD (2)



Baeza-Velasco, Sinibaldi, Castori 2018



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## Understanding Dysautonomia and Orthostatic Intolerance

- **Dysautonomia** means autonomic nervous system (ANS) dysfunction
  - The ANS includes:
    1. **Parasympathetic nervous system** (calming drive)
    2. **Sympathetic nervous system** (alerting drive, linked with stress response)
- Dysautonomia is often associated with **Orthostatic Intolerance (OI)**, **the phenomenon of experiencing symptoms when standing upright** (due to insufficient blood supply to the brain)
- Orthostatic intolerance may be:
  - Linked with lax collagen in walls of blood vessels (impaired contraction)
  - Linked to dysregulated autonomic function, through another mechanism
- Orthostatic intolerance symptoms are exacerbated by *heat, dehydration, high altitude, alcohol and large meals*



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## Understanding Orthostatic Intolerance

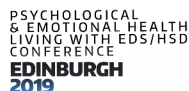
### Acute OI

- Results in *dizziness, light-headedness, visual disturbance* and, on occasions, *loss of consciousness* when standing
- Easy to recognise as dramatic symptoms presenting acutely

### Chronic OI

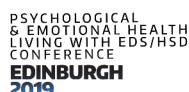
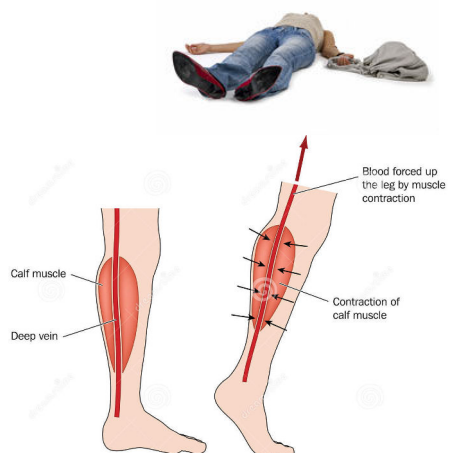
- A less defined, more vague clinical presentation that is present on most / all days
- Symptoms include **inattention/brain fog, anxiety, memory issues, sleep problems, headaches, fatigue and sensitivity to heat**
- Less easy to recognise due to chronicity





## The body's response to OI:

- The primary (conscious) response to OI is for the patient to **lie flat**, allowing more effective perfusion of the brain
- Similar effects may occur by **pumping the calf muscles** (through pacing, leg bouncing, shifting position)
- Another response is the **activation of the stress response** (to help get blood to the brain)
  - *Adrenaline release causes increased heart rate / blood pressure, nausea, anxiety and sweating*
  - *Blood diverted away from the frontal lobes and preferentially directed to subcortical regions, the survival centres of the brain (to facilitate quickened reactions in a crisis)*



- Symptoms of ADHD include:

- Inattention / Distractibility
- Memory impairment
- Impulsivity
- Hyperactivity / Restlessness (and inability to sit still)
- Anxiety
- Mood instability



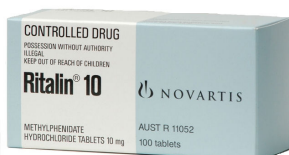
**(Note: ALL these features could be explained by OI)**



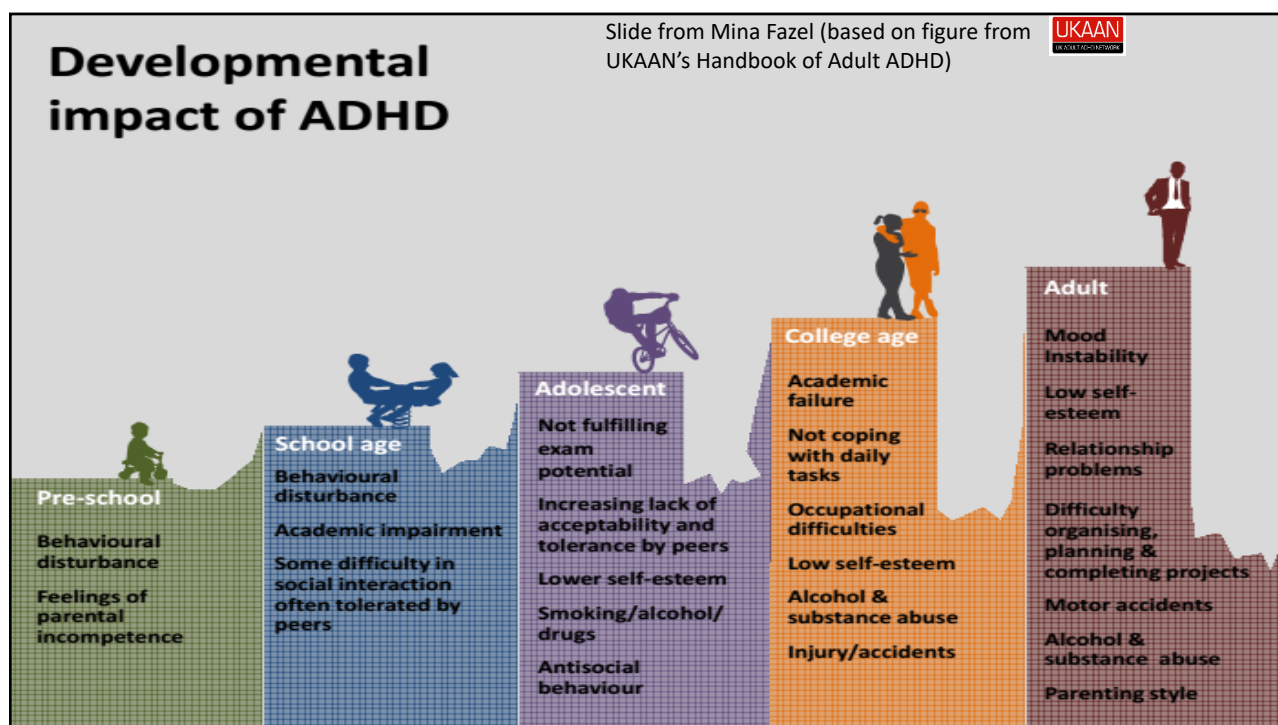
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## Parallels between Chronic OI and ADHD

- ADHD symptoms follow a **trait-like course**, with little variation over time, similar to chronic OI
- ADHD, like many causes of OI, has a **genetic basis** (high heritability)
- Both ADHD and OI cause **significant impairment**



- ADHD is usually treated with stimulant medication like Ritalin, a side-effect of which is blood vessel constriction and increased blood pressure (which helps to reverse OI)





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## Introducing Imogen

*(Video clip 1)*



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## Case Study – Imogen (1)

*(Consent granted to present case)*

- **18 year old** single female, currently doing A Levels  
(having to repeat a year due to physical and mental health problems)
- **Anxiety and sleep issues** since childhood – in recent years has used **alcohol and cannabis** to self-medicate
- Longstanding **mood instability** and at least one episode of **depression**.  
Struggles particularly with **anger management**
- **ADHD diagnosis** aged 16 – tolerability issues with most of the ADHD medications tried
  - Currently taking ER Guanfacine (Alpha 2 agonist) which is helping concentration but at higher doses exacerbates orthostatic intolerance



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## Case Study – Imogen (2)

*(Consent granted to present case)*

- **Recently diagnosed h-EDS**
  - **Family history** of ‘hypermobility’
  - Lifelong history of **joint hypermobility** with recurrent dislocations / subluxations, injuries and pain
  - Associated **systemic features**:
    - Urinary problems
    - IBS
    - Acid reflux
    - Astigmatism
    - Thin skin that bruises / scars easily
  - A strong history of both **acute and chronic OI** including recurrent faints, dizziness and palpitations on standing, visual symptoms, migraines and sleep disturbance (PoTS ruled out)



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## Imogen's experience of Orthostatic Intolerance

*(Video clip 2)*





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## Case Study – Imogen (3)



### Interventions that have helped:

- Pilates with specialist in hypermobility issues (focus on strengthening core muscles)
- Use of compression stockings
- Increased hydration (and salt)
- Calf pumping when feeling dizzy or light-headed
- Treatment of the ADHD with medication
- Effective treatment of pain (Pregabalin under consideration)



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## Imogen's reflections on what helps

*(Video clip 3 and 4)*



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## Particular Challenges of having ADHD and EDS

1. **Diagnosis and differentiation** of symptoms
2. **Compounding** of one disorder's symptoms by the other
3. Significant **mental health burden** associated with both
4. Impulsivity and risk-taking behaviours (of ADHD) increases chance of musculoskeletal **injuries**
5. ADHD impairs the ability to optimally manage EDS and can result in:
  - **Poor medication adherence**
  - **Poor engagement** with health professionals (especially physiotherapy) and rehabilitation programmes



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## Particular Challenges of having ADHD and EDS

6. **Substance use** (often associated with ADHD) can negatively impact management of EDS and aggravate symptoms of OI
7. **Significant stigma and a lack of knowledge** by health professionals
8. **Under-resourcing and deficiencies in service provision**
9. High rates of **tolerability issues** with medications



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## What Needs to Change?

- ☐ **Education** of health professionals (ADHD, rheumatology, general practice)
- ☐ Development of **specialist services for HSD** (that screen for ADHD)
- ☐ Further **research** into the overlap between HSD and ADHD
- ☐ **Screening** for HSD in patients presenting with ADHD (or anxiety)
- ☐ Raising awareness about simple, **conservative management** approaches  
e.g. increased fluid and compression stockings (can be very effective)
- ☐ Development of **new medications** for OI



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## A personal account of living with Hypermobility and ADHD

*"I recently discovered that I have both ADHD and hypermobility. What I found most helpful was gaining an appreciation of the wider impacts of both the hypermobility and ADHD.*

*"My hypermobility means that I hold a lot of tension and that by altering my posture and strengthening certain muscles (which I'm doing through pilates) - I can release that tension and feel more relaxed.*

*"After receiving a diagnosis (of ADHD) I found that my anxiety decreased and my self-esteem improved. I gained an appreciation of the ways in which ADHD was causing these aspects...allowing me to be more sympathetic to myself.*

*"I have also found it very beneficial to learn about how my hypermobility and ADHD can be connected, for example in the link between my blood circulation and my ability to concentrate..... some small changes, such as wearing flight socks, drinking more water and eating salty snacks, have significantly improved my concentration."*



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Thank You