

2023 EDS ECHO SUMMIT

HYPERMOBILITY SPECTRUM DISORDERS

PRESENTATION

Coping with autonomic symptoms

SPEAKER

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Outline

- Case example
- Approaches to management
 - Consider co-occurrences and optimise management of and support for them
 - Think bio-psycho-social
- Summary



Case example - Zeena

- Very active young person
- Combining work and study
- Competing sport at top level



Case example - Zeena

- New onset
 - Heat intolerance
 - Dizziness
 - Palpitations
 - Nausea
 - Aggravated by standing, showering

Case example - Zeena

- Debilitating symptoms
- Struggling to get right referrals and investigations
- Mental health challenges – interlinked or diagnostic overshadowing?

Case example - Zeena

- Ultimately diagnosed
 - hEDS
 - POTS
 - MCAS
 - Autism
 - ADHD

Case example - Zeena



- Importance for Zeena of having a reason WHY
 - Doesn't change the reality of having multiple health conditions/differences
 - Does change self-understanding and approach

Case example - Zeena

- Importance of toolkit (literal and figurative)
- Importance of adaptations, accommodations and adjustments



Approaches to management

- Identify co-occurrences
- Get appropriate support
 - E.g. EDS GP toolkit as good resource
- Applies to both patient and clinician



Approaches to management



- Biological
 - Trial medications
 - Self-management techniques
 - Increase salt in diet (around 9g daily)
 - Keep hydrated (2 ½ to 3 litres daily with electrolytes)
 - Pump calves before standing (calf pump mechanism pushes blood from legs up to heart)
 - Small meals
 - Exercise
 - Think about elevated arm positions
 - Compression stockings
 - Keep moving
 - Avoid sudden changes in posture
- Excellent resources e.g. PoTS UK

Approaches to management

- Think Brain-body
 - Living with and navigating chronic illness is hard
 - Seek help for psychological needs
- Social
 - Discuss and request reasonable adjustments/accommodations in work and education
 - Role of occupational health/government initiatives such as Access to Work

Summary



- Recognize that living with (and navigating care for) chronic illness can be really hard
- Identify and optimize co-occurrences
- Think bio-psycho-social



Thank you
for listening