

2023 EDS ECHO SUMMIT

HYPERMOBILITY SPECTRUM DISORDERS

PRESENTATION

Lifestyle Strategies & Self-Pacing for those living with HSD

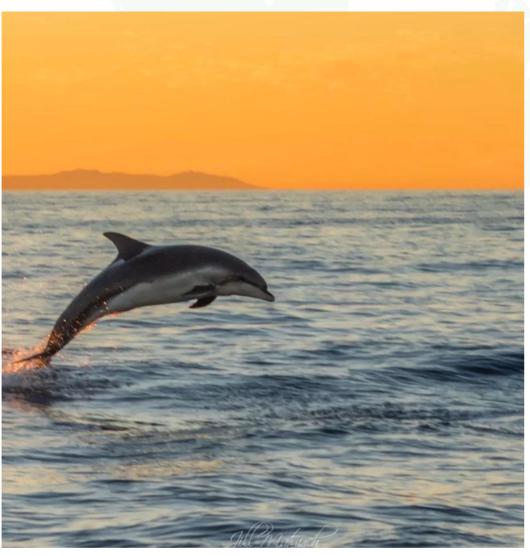
SPEAKER

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No disclosures







Hypermobility Spectrum Disorder: Seeking, exceeding and then setting new boundaries



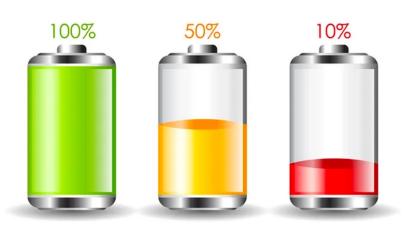
- Hypermobile joints can cause pain when continually or rapidly moved past optimal range
- Similarly, exerting the whole body past its limit results in symptoms
- When a connective tissue, stimulation or energy limit is reached, protective responses can occur



The opposite of pacing and self managing in HSD



- Over-exertion
- Pushing through
- Experiencing an "adrenaline surge"
- Booming and busting
- Depleting resources

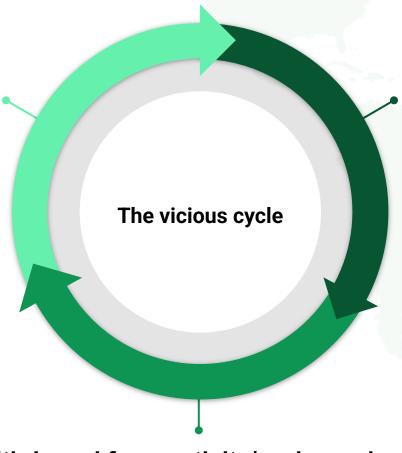


The consequences of not pacing and self managing



Over-exertion/insufficient rest

Excessive load, awkward postures, increase in sympathetic nervous system activity, body senses danger, adrenaline release, blood away from GI tract and towards extremities, emotional distress



Onset of HSD symptoms

Pain, muscular tension/guarding, fatigue, autonomic dysfunction, headaches, gastrointestinal problems, anxiety

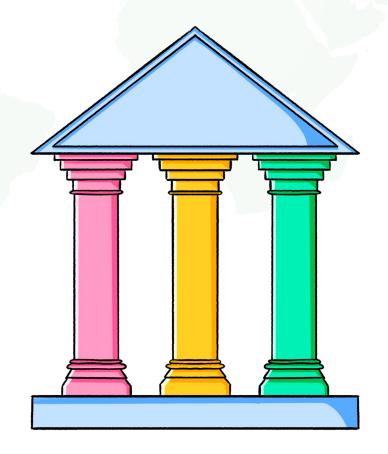
Withdrawal from activity/prolonged rest

Can cause deconditioning, postural pain, low mood, reduction in functional capacity

The 3 Pillars of Pacing



- 1. Identify your current load and symptoms
- 2. Add breaks and boundaries
- 3. Softening the load on your hypermobile self



1. Identify your current load and symptoms

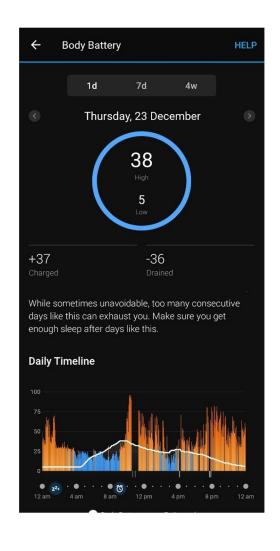


06:00			
07:00	Woke Up; hydrated; read	feeling rested	
08:00	Made breakfast & band prep	mildly dizzy; no sick feeling after eating	Ate 2 eggs & 1 toast
09:00	Full shower Routine	racing heart rate, breathless, tired	
10:00	Resting	breathless from previous activities	
11:00	changed sheets & did dishes	breathless & racing heart	
12:00	church work	still breatless	
13:00	meeting	shaky	
14:00	movie	edgy & high heart rate	Lying down
15:00	movie	edgy & high heart rate	Elevated feet
16:00	Reading	Heart rate calming	

Activity legend (physical, ment	tal, environmental, so	cial)
high demand/stimulation activity		
moderate demand/ stimulation ac	ctivity	
low demand/stimulation activity		
relaxation activity		
* emotionally stressful activity		

1. Identify your current load and symptoms





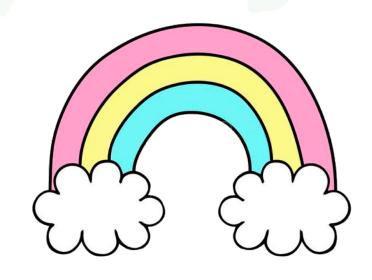




2. Add breaks and boundaries



- Activity diary "like a rainbow"
- Aiming for "green time" before and after big activities
- "Green moments" during activities as well
- Setting a timer
- Match the type of rest to the type of activity



3. Softening the load on your hypermobile self



 Physical: Postural supports, splints, cushions, muscle strengthening*, increasing fitness*, breathwork, feet elevated

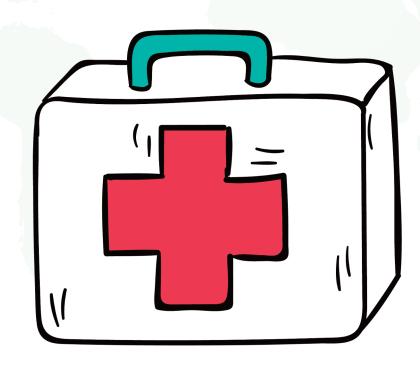
 Mental: Single focus, prioritise, reduce intensity, delegate, postpone

 Social: Consider sensory environment, bring your comforts, limit duration

"First aid" for over-exertions

- Recognise that this has occurred
- Debrief with a trusted person
- Be kind to yourself
- Soothe the body and nervous system
- Reduce upcoming commitments
- Sensory calming: bath, bed, touch, compression, weighted blanket, heat pack







Thank you for listening