

# INFORMATION ON JOINT HYPERMOBILITY SYNDROMES AND THE REHABILITATIVE PROCESS

Dear colleague,

Your patient has been diagnosed with hypermobility spectrum disorder (HSD) or hypermobile Ehlers-Danlos Syndrome (hEDS), classical, or classical-like Ehlers-Danlos Syndrome (cEDS, dEDS).

What these syndromes have in common and are characterized by is an alteration in collagen fiber structure, creating changes in interstitial tissue and collagenous structures such as bones, teeth, ligaments and tendons, skin, intestines and blood vessels, although involvement varies from individual to individual. The cause is thought to be genetic, but the phenotype can be affected by phenomena such as inflammation, injuries and co-morbidities. These structures will generally be “softer”, less functional and more prone to injury, and may heal slower.

In terms of the musculoskeletal system, some of the main manifestations of these conditions tend to be greater than average joint ROM, and especially in the younger patient, often greater than average flexibility. This often leads to the patient being perceived as fit. However, unless supported by active joint stabilization, the greater joint mobility also manifests as joint instability, and many complaints in these patients are directly or indirectly caused by this. Global muscles, at least in some areas, often have a higher resting tone, which represents a dysfunctional compensation with these muscles for the decreased joint stability.

The rehabilitative process will therefore need to be adapted to the patient’s unique and specific needs. There needs to be a greater attention to basic stability of proximal joints and close guidance of exercise form prior to any progress to strengthening. Patients are often

used to and expecting to be in pain, tend to be SNS dominant, and may need prompts to perform exercises carefully, without resorting to tension, in a pain free manner and range.

Proprioception tends to be decreased, and patients often suffer from comorbidities such as POTS and MCAS. Other comorbid conditions include, but are not limited to: Migraines, Chiari malformations, tethered cord, vascular compression syndromes, depression and anxiety, gastrointestinal disorders, small-fiber neuropathy etc. Patients often present with a high SNS tone. Symptoms directly derived from the joint instability and tissue fragility tend to be myofascial pain, joint pain, tendinopathies etc. Some degree of central sensitization is often present due to chronic pain that has gone untreated. Physical therapy interventions, when incorrectly applied, without attention to the unique characteristics and needs of the patient with symptomatic joint hypermobility, may worsen symptoms, and should therefore be approached thoughtfully, gradually, and with the clinical picture in mind.

Be aware of and look for:

- Potential cervical instability, which may necessitate specific attention and treatment, and may affect tolerance of other therapeutic exercise interventions and positions.
- Tendency towards subluxation, dislocations and poor joint mechanics in general.
- Subluxations may occur in any joint, including sternocostal, costovertebral, vertebral, any pelvic joint, temporomandibular, hip, glenohumeral etc. and this tendency necessitates, among other interventions, stabilization straining and improved body mechanics and general bodily alignment.
- Decreased proximal stability and consequent compensatory movement and stabilization patterns
- Pain levels and location may vary from day to day, and may be affected by co-morbidities such as MCAS or the greater predisposition to overloading tissues due to lack of stability and proprioception.

- Energy levels that may vary from day to day. Encourage patients to engage in a steady level of activity instead of fluctuating levels of inactivity and increased activity. Encourage health lifestyle practices in general in order to maximize potential for tissue regeneration and energy.

Resources:

<https://www.ehlers-danlos.com/healthcare-professionals/>

<https://www.ehlers-danlos.com/wp-content/uploads/2017/05/hEDS-Dx-Criteria-checklist-1.pdf>

<https://www.wendy4therapy.com/upper-cervical-instability>

<https://www.ehlers-danlos.com/eds-types/>

<https://www.lilianholm.com/physical-therapy-for-hypermobility-disorders.html>

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