

Top tips for doctors on hypermobile Ehlers-Danlos Syndrome (hEDS) and Hypermobility Spectrum Disorders (HSD)

1. **“If you can’t connect the issues, think connective tissues.”** Non-specific and medically unexplained symptoms are usually real and should not be dismissed.
2. HSD/hEDS are **“not-so-benign multisystem disorders”**. Symptoms vary hugely over time, often worsening with age. A holistic approach is needed, bearing in mind the patient’s previous healthcare experiences may have been poor.
3. Enquire about family members; these are hereditary disorders of connective tissue so **positive family histories** are common.
4. **Validation of symptoms by healthcare professionals can be immensely helpful** to both patients and their families. Patients value their doctors learning about the complexities of HSD/hEDS. Many will feel relief to finally have an explanation for their multiple symptoms.
5. Symptoms can be managed, and **quality of life can be improved**.
6. **Don’t miss treatable conditions**; more than one pathology may co-exist. Autoimmune conditions, heart rate and blood pressure anomalies, gut dysmotility and vitamin/mineral deficiencies are especially common. New symptoms should be investigated with this in mind.
7. **Children can present with symptoms of HSD/hEDS** including abdominal symptoms or growing pains. Fear of ‘labelling’ a child with a diagnosis may result in delays in access to appropriate care. Earlier identification enables earlier intervention and may prevent progression to more serious problems later.
8. Children may also present with **neurodevelopmental disorders** such as hyperactivity, inattention, dyspraxia, autistic spectrum disorder, sleep and food issues, emotional problems, hypersensitivity and anxiety.
9. **Parents of children with HSD/hEDS commonly have the disorder themselves** and are generally not projecting their own health issues onto their children. They may be more astute at noticing subtle symptoms, and probably know more about the condition than you, so listen with care.
10. **A low Beighton score does not exclude HSD/hEDS**. Patients stiffen with age so their Beighton score may decrease, although pain may worsen. The extent of multi-system symptoms is not related to the Beighton score.

1. Phrase used by Dr Heidi Collins

2. *Joint hypermobility syndrome in childhood. A not so benign multisystem disorder?* N. Adib, K. Davies, R. Grahame, P. Woo, K. J. Murray; *Rheumatology*, Volume 44, Issue 6, 1 June 2005, Pages 744–750

3. *A connective tissue disorder may underlie ESSENCE problems in childhood*; Carolina Baeza-Velasco, Rodney Grahame, Jaime F. Bravo, *Department; Research in Developmental Disabilities*, 2016