Hypermobile Spectrum Disorders

Disorders characterised by collagen abnormalities. Range from increased hyper mobility with no other problems (20% of population), through hypermobility with other issues that can be significant (no genetic abnormality identified) to Ehlers – Danlos Syndrome (13 genetic varieties described). The Beighton Scoring system (https://www.ehlers-danlos.com/assessing-joint-hypermobility/) measures hypermobility but from a practical perspective ask about ability to hyperextend fingers.

10 years to achieve a diagnosis and invariably management poor and crosses many specialties

Possible associated symptoms:

70% have headache. Migraine is the most common but other possibilities are Chiari, neck instability (may need upright MRI), CSF leak, IIH. May be overlap.

POTS. High resting heart rate , standing heart rate increases by 30 per minute within 10 minutes of standing , fluctuating symptoms of syncope. Feels awful when up right, worse after meals, exertion, warm environments. disproportionately disabled.

Mast cell activation. Urticaria, flushing, dermatographia. Not IgE related. Asthma, rhinitis,

Chronic fatigue, brain fog.

Musculoskeletal pain.

Anxiety.

Other autonomic dysfunction include gastric and bladder problems.

Mitral valve problems.

Useful resources

https://www.rcgp.org.uk/clinical-and-research/resources/toolkits/ehlers-danlos-syndromes-toolkit.aspx

https://www.ehlers-danlos.com/

https://www.potsuk.org/