Symptomatic Joint-Hypermobility Guide

A heritable disorder of connective tissue (HDCT), EDS (Ehlers-Danlos Syndromes) includes 14 different subtypes with hEDS (hypermobile EDS) being by far the most common (yet does not have known genetic markers). The clinical presentation is highly variable amongst people with the same EDS type and between different EDS types. Core features also include hyperextensible (stretchy) skin and tissue fragility. Patients with Hypermobility Spectrum Disorders (HSD) have symptomatic joint hypermobility but do not have another condition to explain their symptoms. Dysfunction occurs in virtually any organ or tissue.

What to Look for

Symptoms

- Joint instability (dislocation or subluxation [partial dislocation]), including cervical instability
- Overuse/recurrent injury
- Chronic pain
- Headache (e.g., migraine)
- Jaw pain and dysfunction (i.e., TMD)
- Fatigue
- Sleep disturbance
- Gastrointestinal dysfunction (e.g., constipation, heartburn, diarrhea, nausea, vomiting)
- Orthostatic intolerance (difficulty tolerating upright posture)
- Urogenital (e.g., frequent urination, painful periods, painful intercourse)
- Mast cell disease (e.g., flushing, hives, itching, wheezing)

"Symptoms" are what you feel.
"Signs" are what you can see.

Signs

- Joint hypermobility (increased joint range of motion -- now or in the past)
- Recurrent injury (e.g., sprains, strains)
- Soft, velvety and/or stretchy skin
- Fragile tissues (skin, bone, blood vessels, organs)
- Easy bruising
- Unexpected stretch marks
- Atrophic scarring/poor wound healing
- Hernias (e.g., abdominal, inguinal, umbilical)
- Rectal/uterine prolapse
- Dental crowding
- Eye problems (e.g., myopia, strabismus, blue sclera)
- Scoliosis
- Pectus (breastbone) deformity
- Arachnodactyly (long fingers & toes)
- Low bone density
- Flat feet
- Mitral-valve prolapse
- Neurodivergence (e.g., autism, ADHD)
- Tethered cord
- Chiari malformation

The Five-Part Questionnaire for Generalized Joint Hypermobility

1. Can you now (or could you ever) place your hands flat on the floor without bending your knees?
2. Can you now (or could you ever) bend your thumb to touch your forearm?
3. As a child, did you amuse your friends by contorting your body into strange shapes OR could you do the splits?
4. As a child or teenager, did your shoulder or kneecap dislocate on more than one occasion?
5. Do you consider yourself double-jointed?

Endorsement of two or more questions suggests generalized joint hypermobility.

Comorbidities

Mast Cell Activation Syndrome (MCAS) -- Symptoms may include flushing, hives, itching, wheezing, chemical, drug, and/or food intolerances and anaphylaxis.

Dysautonomia (POTS, etc.) -- Symptoms may include difficulty tolerating upright posture, temperature intolerance, fast heart rate, fainting or feeling faint, brain fog, nausea, and/or vomiting.

Red Flags for Genetic Testing

suggest a genetically defined type of EDS or other HDCT

- Sudden, early unexpected death (under age 40) in your family
- Organ rupture
- Extremely stretchy or fragile tissues / skin and/or translucent skin
- Club foot
- Congenital hip dislocation
- Muscle weakness or low muscle tone (hypotonia)
- Hypermobility limited to hands and feet
- Aortic or arterial aneurysms, dissection, or rupture
- Severe progressive valvular heart disease
- Pneumothorax
- Marfanoid habitus (tall/lean) and/or aortic root changes

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Medical Advice Disclaimer
This information is purely educational and does not intend to be a substitute for personalized medical advice. Always consult with your doctor to determine what tests and treatment are right for you.

References
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