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# EDS 101

## Your "elevator speech"

**What is Hypermobile EDS?**

Hypermobile EDS (hEDS) is an inherited disorder of connective tissue and its collagen protein. It is defined as a syndrome by the association of the following conditions that tend to occur together: generalized joint hypermobility, joint instability complications, systemic musculoskeletal pain, and unique skin features. It may also include pelvic dysfunction, cardiovascular symptoms, autonomic nervous system dysregulation, anatomical variants, GI dysfunction, difficulty with balance, anxiety and/or mast cell activation syndrome (MCAS) or postural orthostatic tachycardia syndrome (POTS). Research is beginning to demonstrate that these other conditions are linked to hEDS and not just arising independently. The prevalence of hEDS is estimated to be 1 in 5000 people. Although suspected to have a genetic marker associated with the expression of hEDS, one has not yet been identified.

**What is joint hypermobility?**

Normally, our musculoskeletal system is designed to maximize function while minimizing injury. When ligaments don't resist tension as they should, when resting muscle tone is poor, or when joint sockets are shallower than they should be to tolerate a particular mechanical load, this can result in joints that move more than they safely can move. Without symptoms, this is considered an anatomical variant and someone might just be described as "flexible." When the body sends pain signals to the brain, it requires attention as continued misuse will likely result in undesirable symptoms.

**What is collagen?**

Collagen is the name of the protein that forms the building blocks of connective tissue and gives it structure and strength. Its intended purpose is to resist deformation while providing a matrix for support of tissues like skin, blood vessels, tendons/ligaments and as scaffolding or protection of internal organs. When it is not working as intended, skin stretches and breaks easily, wounds don't heal well, blood vessel walls are weak and rupture or cause excessive bruising, tendons and ligaments are too elastic and "sprain" or easily "tear" and internal organs move around too much and "prolapse" or "herniate."

Source: Wendy4Therapy

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# Hypermobile EDS

## Common Symptoms Reported

*Each individual may have a mixture of different symptoms! There is NO requirement to have all of these symptoms!

| | |
|---|---|
| **Pain** | Widespread, chronic, doesn't correlate with radiographic results |
| **Source of pain** | Head/neck, jaw, wrists, fingers, back, SIJ, low back, muscle spasms |
| **Joint Mobility** | Unstable, hypermobile, excess range, frequent subluxation, braced |
| **Endurance** | Poor exercise tolerance, severe fatigue, deconditioned |
| **Function** | Orthostatic Intolerance, requires rest to function, school/work hard |
| **GI/Digestion** | Constipation, nausea, multiple food allergies/intolerances, ED, pain |
| **Psyche** | Disabling Anxiety, depression, fear of getting hurt, medical trauma |
| **Social** | Socially Isolated, can’t keep up with peers, experiences shame |
| **Neuro** | Headaches, clumsiness, brain fog/word finding, numbness |
| **Cardiac** | Palpitations, poor exercise tolerance, low BP, POTS |
| **Allergy/imm** | Excessive Mast Cell reactions, multiple food/chemical allergies |
| **Sleep** | Difficulty Falling/staying asleep, extreme fatigue, constant arousal |
| **Skin** | Soft skin, poor wound healing, stretch marks, allergy to adhesive |
| **OB/GYN** | Premature Labor, pelvic organ prolapse, pelvic pain, incontinence |
| **Physio** | Lots of PT, may have had a negative experience, fear of movement |

Source: Wendy4Therapy

*Please Note*: Your physiotherapist is not a medical doctor and is not licensed to provide an official medical diagnosis. Education provided here is for your information only.

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# Dysautonomia 101

(dys-function of the autonomic nervous system)

**Autonomic Nervous System Dysfunction (involuntary control)**

- Heart rate, digestion, breathing, perspiration, body temperature, involuntary muscle activation, salivation.
- The body has three regulatory nervous system pathways that are always "on" and monitoring the body.
- The body has a tendency to only want to activate one of these systems at a time.
- **Sympathetic** nervous system controls heart and skeletal muscles and prepares your body to "fight or flight"
    - increases heart rate by activating the muscles around the heart, dilating and tightening blood vessels to get more blood to body muscles to be able to "run away from the lion" or get more blood to your brain (keep it from pooling in your feet) when you stand up
- **Parasympathetic** nervous system controls things like digestion and urination
- Resulting symptoms from autonomic nervous system dysfunction (aka dysautonomia) depends on the organ system most affected by the broken feedback loop:
    - lightheadedness with standing, palpitations, blood pressure and HR fluctuations, abnormal dilation of pupils (blurry vision), excessive fatigue/thirst/sweat, difficulty with swallowing, slow digestion, bloating, constipation, acid reflux from delayed gastric emptying, incontinence, poor temperature control, heat intolerance, variable anxiety, disturbed/non-restful sleep, allodynia
- It's been found that there is a correlation between the number of joints affected by hypermobility and the higher degree of autonomic dysfunction
- **POTS** vs orthostatic intolerance: POTS is defined as a rise in heart rate of greater than 30 beats per minute after 10 minutes of standing from supine. People with POTS typically don't also have a decrease in blood pressure (some do). Drop in blood pressure with standing is called "orthostatic intolerance."
- **MCAS**: the body's inappropriate defense against a benign intruder, a histamine response

**POTS**

| Symptoms | Treatment suggestions |
|---|---|
| Heart rate increases upon standing<br>BP tends to decrease, HR increases<br>Palpitations<br>Dizziness<br>Blood pooling in legs<br>Near fainting or fainting<br>Brain fog/difficulty concentrating | Rest, awareness of symptoms, pacing<br>Increase fluid/salt intake<br>Compression garments<br>Exercise beginning in supine and with legs<br>Change positions slowly<br>Manage body temperature<br>Medications |

**MCAS** (similar in that it's a broken feedback loop but not officially dysautonomia)

| Symptoms | Treatment suggestions |
|---|---|
| Skin: hives, flushing, itching, swelling<br>GI: Nausea, abdominal pain, vomiting<br>Pulmonary: shortness of breath, wheezing<br>Neuro: hyperalgesia, headache, brain fog, confusion, irritability | Avoidance of triggers<br>Physiological quieting (meditation, yoga, tai chi)<br>Antihistamine, mast cell stabilizing and anti-inflammatory medications |

Source: Wendy4Therapy

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# General HELPFUL HINTS

**Things to AVOID**

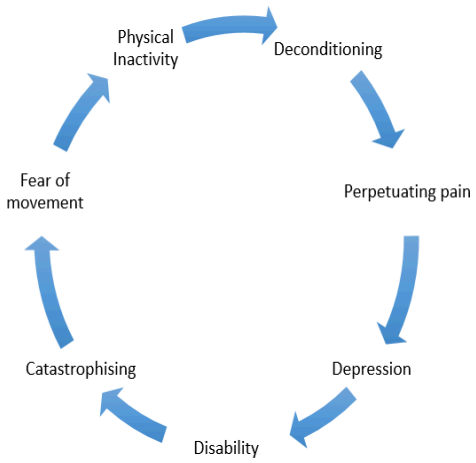
- Hyperextension or locking out joints
- High impact jumping, roller coasters, contact sports
  Heavy push/pull/lift
- Most stretching
- Head/neck in dependent positions (hands/knees, plank, bike riding, freestyle swimming, texting)
  Hyperextension of joints (over stretching, hands/knees, heavy hand weights)
- Repetitive activity (including resting, sitting, standing too long)
  Overcommitting to emotional, social or physical activity

**Precautions for surgery**

- Less likely to be successful in patients with
  EDS Tissues more fragile and take longer to
  heal Blood vessel fragility increases bleeding
- Special considerations for skin sutures: stitch closer together, leave sutures in longer
  Consider pre-medicating for MCAS and POTS

**Tips for Success**

- Protect the joints from hyperextending
  Strengthen muscles that cross unstable
  joints More reps, less weight to avoid
  microtrauma Start low, go slow
- Make sure pelvic floor and abs are strong before progress
  Exercise is your MEDICINE. You may have to work harder than
  others. Consider alternative forms of exercise: aquatic, tai chi,
  yoga




**Have a flare plan**

- Supportive pillows
- Easy to prepare snacks & meals
- Pills, creams, meditations, ER/"Go bag" ready to go
  Back up plan for work/childcare/housework

**Have an ER plan**

- Medical history on paper, meds current
- Explanation of EDS (see EDS website for emergency card to present)
  Educated advocate to go with you.

**But...don't be afraid to move! Movement is your medicine.**

Source: Wendy4Therapy

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# PACE your activity

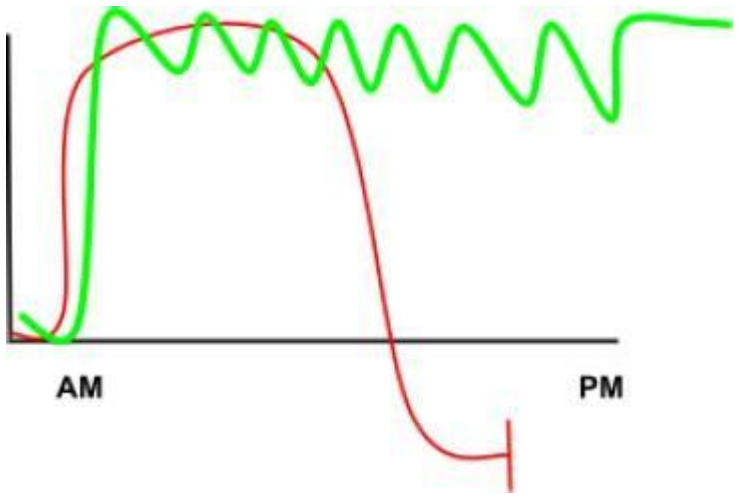
"Do a thing…REST…Do a thing…REST…Do a thing…REST……"

**P** - Plan your daily activities building in time for rest
**A** - Adapt the home environment, adequate rest, assistive equipment, ask for help
**C** - Conserve energy, check in with medical providers, cool temperature
**E** - Emotional stability, exercise in moderation, eliminate unnecessary tasks

Sample schedule...

| | |
|---|---|
| 9 - 10am | Eat breakfast |
| 10 - 10:15am | Rest |
| 10:15 - 11am | Check computer |
| 11 - 11:15am | Rest |
| 11:15 - 1:15pm | Run errands |
| 1:15 - 1:30pm | Rest |

Suggestions for your **MICROBREAKS**: use braces, support your body with pillows, breathe, use heat to soothe, ground yourself feeling the surface that is supporting you, weighted blanket, pet your dog, get fresh air, elevate your feet…then reset your timer for your next break!




Source: L. Russek, PT, PhD