World-renowned EDS expert, rheumatologist Professor Rodney Grahame (University College London) points out that, in America, almost 650,000 cases of EDS are missed ANNUALLY, based on studies that suggest almost 95% of cases presenting to clinics are missed, most often diagnosed with other things (Fibro/ME/csf, etc.).

SYMPTOM LIST

Do you or close family members (parents siblings children) have any of these?

[FAMILY HISTORY IS IMPORTANT AS IT IS A GENETIC ILLNESS

Migraines, allergies, hay fever, asthma, excema, varicose veins, postive Gorlin's sign (ability to touch your nose with your tongue), IBS, gastric reflux, hernias, diverticulitis, bendy joints or hyperflexibility, soft skin, easy bruising and bleeding, slow wound healing thin translucent skin that you can see the veins through or unusual scarring especially on the  lower legs. Unusual stretch marks.

Joint pains, arthritis, TMJ, RSI, aneurysms and mitral valve problems. Also POTS/OI and ME of course - fainting dizziness etc. Overcrowding of teeth (orthodontic work needed), scoliosis. Unstable joints/proneness to sprains, dislocations, subluxations and hyperextension. Joints that click, early onset of osteoarthritis, chronic degenerative joint disease, muscle pain, frequent tearing of tendons or muscles, Reynaud's phenomenon, Dupuytren's contracture, scoliosis, costochondriatis, pectus scavatum, nearsightedness and other eye problems, blue sclera, carpal tunnel, neuropathy, keratosis pilaris (pimply red rash on upper arms that comes and goes), skin tags (small longish pedicles of skin overgrowth on various parts of the body) and pregnancy complications such as post-partum hemorrage.

\*TMJ = temperomandibular joint dysfunction - i.e. a saw jaw that hurts to chew or open your mouth.

YOU do NOT need to have ALL these sympotms ot have EDS and few will have them all but your gfamly members may have some and you will have some others.

The symptom list is so diverse as EDS is a connective tissue disease (CTD) and CT is nearly everywhere in the body; symptoms vary form person to person, even within the same family.

Other possible  symptoms - dry lips, alcohol intolerance,  clumsiness (?possibly due to poor proprioception) ganglions - eg on the wrists and a youthful appearance-few wrinkles, petechiae (tiny red dots of blood just under the skin that appear for no apparent reason). Ear problems like "water in ear" or blocked ear feeling and tinnitus. Also avoidance of social situations can be a sign-they can be stressful and can involve a lot of standing, in hot, crowded places and often alcohol (a vasodilator)- all factors that can exacerbate EDS symptoms.

There are many types of EDS and much crossover between the types - you do NOT need to be hypermobile or flexible to have EDS, as is commonly but wrongly stated. In fact it seems likely some people with it have very tight muscles by contrast (muscular hpertonicity).

Please copy and share this list widely - the quicker more people get the correct  diagnosis, the sooner we will get research and treatment. Please also copy and share freely any relevant posts of mine in this thread and elsewhere.
......................................................................

My specialist thinks it may all be due in my case to " stretchy veins " in the Ehlers Danlos (EDS) spectrum so that when i stand up i get inadequate blood to the brain

(when tested correctly recently my BP dropped 20mmHg in a minute when i stood up - from 125 to 105 systolic but then returned to 125 within 2 mins) so adrenaline must have kicked in quickly

this instant adrenaline release happening constantly may be the cause of many of our problems  (possibly leading to low cerebral spinal fluid levels too which exacerbates things further)

(Maybe a high protein diet helps as it helps build collagen to strengthen the veins.

IM Vit B12 increases blood volume so may help because of that and my genticist tells me it also is intrinsic - along with Vitamin C (!)  in building connective tisssue in the body.)

certainly since he suggested this i have been observing my position in relation to symptoms and noticing a definite correlation

eg. resting sitting up does me no good so it is not the resting that helps but the lying down

yes i am ill after being upright- no exertion needed
and i am better after a day or two lying down

and it would explain why we have an energy boost sometimes for no apparent reason...eg in the evenings or early mornig.. after lying down for 6 hours or so all day or night...... and the "tired but wired" feeling we often get esp at night.

not wanting to be over simplistic here but would love to know if anyone has researched this aspect of the illness or if anyone else has observed this correlation between posture and symptoms

years of constant adrenaline boom crashes - and resulting in blood sugar boom crashes too - would take its toll on anyone.

 It should be easy to test and even predict crashes according to your position... and yes I know for sure that a certain amount of time spent upright ...even sitting up in a chair doing nothing... will cause me to crash, while after about 2- 3 days of lying flat my symptoms will improve or even disappear.

 Lying down is the first thing we all do for a crash, and in fact most of us feel we would die if we could not lie down in a crash but we never mention it in list of effective treatments

 so it may not be fatigue we suffer at all- rather a need to be horizontal plus aching muscles and joints, headache, swollen tissues of feet and calves due to fluid estravastation and accumulation there...all of which is summed up erroneosly as fatigue. Fatigue is cured by rest and sleep.

I would love to hear everyone’s thoughts on this theory that comes from top orthodox medical sources please.

at a recent EDS conference it seems the list of symptoms closely overlaps thoe of ME/cfs.

So they may be the same disease for at least some of us…and wiki is not very reliable on EDS..it classifies it into types but notes that crossover between the types is common - something people often overlook and try to pin down one type only in a person.

cheers
 Ally