

THE ZEBRA SURVEY

Context questions:

1. Birth year
2. Male/Female/Other
3. National health system that you've been in (with insurance/without insurance)
4. Do you currently have an active medical insurance?
5. Do you have a proof of disability? If yes, what degree?
6. Number of GP/specialist visits within the past year: how many GP, how many specialist
7. Medicine you take regularly, and for what symptoms
8. If diagnosed with EDS:
 - a. How old were you when diagnosed?
 - b. After how many years of symptoms did you receive your diagnosis?
 - c. Did you get your diagnosis: via NHS / private?
 - d. Did you attend a specific EDS clinic?
9. If not diagnosed, how long have you been having symptoms that impaired daily functioning? (in years: 0-1, between 1 and 5 years, between 5 and 10, more than 10)
10. Do you have any direct relatives with EDS, suspected or diagnosed? (yes/no, if yes then: a. suspected or diagnosed, b. what type of EDS)

Content questions:

11. What type of EDS do you have (or strongly suspect you might have):
 - a. Hypermobility EDS (hEDS, also called type III) (Diagnosed/Undiagnosed)
 - b. Vascular EDS (Diagnosed/Undiagnosed)
 - c. Classical EDS (Diagnosed/Undiagnosed)
 - d. Other type (Diagnosed/Undiagnosed)
12. EDS expresses itself in several areas. What is, for you, the area with the most severe issues for you? Choose three.
 - a. GI (abdominal pain, diarrhea or constipation, frequent vomiting)
 - b. General fatigue and low energy
 - c. Muscles and bones (pain, frequent dislocations, subluxations, hip dysplasia, premature arthritis)
 - d. Dental (teeth crammed in mouth space, tooth material too soft)
 - e. Brain (migraines, Chiari malformation)
 - f. Mental health (autism, depression, anxiety, panic attacks, OCD)
 - g. Reproductive tract (problems related to menstrual cycle, sexual dysfunction, miscarriages, issues with pregnancy and birth, genital pain)
 - h. Systemic allergies

*We will take these areas one by one, to locate all or most of your symptoms.
Please tick those that apply to you, according to your current knowledge.*

In the Additional comments box put any extra info that you find relevant to the question.

13. Bowel area:

- a. abdominal pain
- b. diarrhea
- c. constipation
- d. alternating diarrhea and constipation
- e. nausea
- f. abnormal bloating
- g. frequent vomiting
- h. chronic hiccups (not just occasional)
- i. chronic burping (at least 1x per hour, most waking hours, most days)
- j. reflux
- k. hiatus hernia
- l. leaky gut syndrome
- m. IBS (Irritable Bowel Syndrome)
- n. SIBO (small intestine bacterial overgrowth)
- o. food allergies and intolerances:
 - i. lactose
 - ii. gluten
 - iii. histamine
 - iv. oxalates
 - v. other (what)
- p. If you have food allergies, do the reactions occur:
 - i. immediately after ingestion (5-30 min)?
 - ii. with a delay (up to 48h)?
 - iii. sometimes immediately, sometimes later
- q. Additional comments?

14. Muscles and bones area:

- a. joint pain (occasional/often/all the time, barely registering/bearable/completely debilitating)
- b. congenital hip dysplasia
- c. premature arthritis
- d. frequent dislocations
- e. labral tear (at least one)
- f. osteoporosis
- g. marfanoid habitus
- h. unusual flexibility making the body prone to injury
- i. hyperextension at the knees (legs describing an arc when straightened)
- j. One leg longer than the other
- k. Additional comments?

15. Dental area:

- a. absence of tongue frenulum (or much reduced)
- b. absence of lower lip frenulum (or much reduced)
- c. teeth crammed in mouth space

- d. growth of wisdom teeth causing pain due to cramped space
- e. abnormal teeth roots ('S-shaped'), creating difficulties with extraction
- f. soft enamel and dental tissue, resulting in teeth sensitivity and pain
- g. gingivitis (inflammation of the gums)
- h. gum recession
- i. 'ground' teeth appearance (as if someone 'shaved' the tops off)
- j. Additional comments?

16. Brain-related area:

- a. Migraines
- b. Tension-type headaches
- c. Chiari malformation
- d. Cranio cervical instability
- e. Tethered cord syndrome
- f. Spontaneous CSF (Cerebrospinal) leak
- g. chronic runny watery nose
- h. Brain fog
- i. Nausea
- j. Unable to regulate temperature
- k. Cognitive dysfunction (such as attention deficit, memory loss, slow processing of information)
- l. Misophonia (an unusual sensitivity to sounds)
- m. Synaesthesia (seeing letters in colour, tasting sounds, etc. – unusual sensory connections)
- n. Dyslexia or dyscalculia
- o. Hyperlexia or hypercalculia
- p. Reduced motor control (may be temporary, such as 'in the morning')
- q. Tingling in hands, arms, or feet
- r. Tinnitus
- s. Additional comments?

17. Genital and reproductive tract:

- a. miscarriages or still births (one/two or more/not applicable)
- b. premature childbirth (one/two or more/not applicable)
- c. other issues in pregnancy (such as symphysis issues)
- d. premature infertility (ovaries stop working before 40)
- e. male infertility
- f. early menopause
- g. period pain or cramps (/not applicable)
- h. endometriosis (/not applicable)
- i. PCOS (polycystic ovary syndrome, multiple benign ovarian cysts (/not applicable)
- j. irregular menstruation (/not applicable)
- k. PMS (/not applicable)
- l. erectile dysfunction (/not applicable)
- m. vulvodynia (long-term pain in the vagina)
- n. sexual dysfunction of other sort

- o. Additional comments?

18. Heart and blood circulation:

- a. POTS (Postural Tachycardia Syndrome)
- b. racing heart even when lying down
- c. low blood pressure
- d. light-headedness
- e. fainting, including if related to anxiety-inducing situations
- f. fainting when standing still for longer than a few minutes
- g. dysrhythmia
- h. mitral valve prolapse (including if it was present in childhood and later disappeared)
- i. Additional comments?

19. Respiratory area:

- a. Chronic runny nose
- b. Bronchoconstriction
- c. Wheezing
- d. Shortness of breath
- e. Sleep apnea
- f. "Air hunger" (as if you forgot to take a breath)
- g. Additional comments?

20. Skin:

- a. Unexplained rashes
- b. Itching with or without rash
- c. Severe reaction to bug bites
- d. Skin prone to bruising easily (not remembering where the bruise came from)
- e. Soft velvety skin
- f. "Old lady hands" (excessively wrinkled hands at a young age)
- g. Impaired wound healing
- h. Flushing of face/neck/upper chest
- i. Eczema
- j. Additional comments?

21. Mental health area:

- a. ASD (Autism Spectrum Disorder) (diagnosed/undiagnosed)
- b. Chronic "reactive" depression, in reaction to life situation (such as following loss, traumatic life events, or accompanying hardship)
- c. Chronic depression for more than a year, without any of the causes above
- d. Social functioning impairment
- e. Panic attacks
- f. Anxiety
- g. OCD (Obsessive-compulsive disorder) (diagnosed/undiagnosed)
- h. ADHD (Attention Deficit and Hyperactivity Disorder) (diagnosed/undiagnosed)
- i. Bipolar conditions (diagnosed/undiagnosed)

- j. PTSD (Post-Traumatic Stress Disorder) (diagnosed/undiagnosed)
- k. Self-harm (If yes, at what age)
- l. Suicidal thoughts (If yes, how often/intense)
- m. Do you take any medicine to help with any of these conditions?
 - i. If yes, what medicines and for which conditions or symptoms?
 - ii. Do the medicines help? (yes/no/somewhat; box for comments)
- n. Additional comments?

22. Systemic allergies:

- a. MCAS (Mast Cell Activation Syndrome) (diagnosed/undiagnosed)
- b. Allergies to environmental triggers (such as mold, dust, pollen, animal hair)
- c. Chemical triggers (ingested, such as medicines (which?), an allergic reaction to alcohol, etc.)
- d. Histamine intolerance (diagnosed/undiagnosed)
- e. Asthma or respiratory issues triggered by allergic reaction
- f. Have you ever needed to carry an EPI Pen due to risk of anaphylaxis?
- g. Severe itching and wounds from chronic itching and scratching, including if in childhood and then outgrown
- h. Additional comments?

23. Other issues:

- a. Reaction to anesthesia: typical/ atypical, if atypical then in what way
- b. Chronic fatigue
- c. Poor quality, not restful sleep (Tired when waking up)
- d. Low thyroid
- e. Dysautonomia
- f. Frequent nosebleeds (including if in childhood, then outgrown)
- g. Additional comments?

Thank you for completing this survey!