Practitioner Guide for EDS Awareness

Facts & Statistics

Approximately 1:5000 people have EDS
There are 13 different types - some are more rare than others
The hypermobility type (hEDS) is the most common, followed by classical EDS (cEDS)
A common thread between them is the hypermobile joints and skin hyperextensibility.

Signs and Symptoms

Individuals may have some or all of the following:

- Stretchy lax hypermobile skin (often only seen when pulling)
- Joint dislocations, subluxations and hernias
- Joint stiffness and arthritic conditions
- Fatigue and all types of insomnia
- Easy unexplained bruising
- Poor wound healing and scarring - varicose veins and stretch marks at young age
- Persistent and frequent viruses or infections
- Chronic local or systemic pain - muscle, joint or bone
- Fluctuations of the nervous system termed Dysautonomia (extreme sympathetic dominance)
- Migraines and headaches
- Anxiety, depression and other psychosocial impairment
- Cardiac features - Aortic Heart Valve and vascular features
- Functional and structural digestive disorders - IBS, SIBO, GORD, gastroparesis, gastritis
- Dental crowding, gingivitis and gum recession
- Menstrual irregularities, pelvic pain, dyspareunia
- Extreme sensitivities to foods/supplements, meds

Referral Options

Naturopath and Nutritionists
Physiotherapist, Exercise physiologist, Osteopath
Psychologists
Specialist cardiologists
GP's with knowledge of EDS

What is EDS

EDS is a genetic collagen connective tissue defect (gene polymorphism), which combined with an epigenetic event or trauma, causes body wide symptoms. It is yet unknown how the gene defect is influenced by the event, very limited research shows mast cell involvement.

There is unfortunately no cure, however many individuals are able to manage their symptoms and live fulfilling lives.

Genetics

A parent of a child with EDS will have the same type of EDS, however the severity of symptoms can be different.

A parent of a child with EDS can be a carrier of the defective gene, although not display symptoms or not have had the polarisation of an epigenetic/traumatic event.

Comorbidities

- Trauma - Medical, psychological or physical
- Chronic Fatigue Syndrome
- POTS, Orthostatic intolerance, Raynaud's phenomenon
- Autoimmune conditions - Coeliac disease common, MCAS, Endometriosis, Fibromyalgia
- Gilbert's Syndrome
- Gastroparesis
- Anxiety/ Depression
- Small fibre Neuropathy
- Cervico-cranial instability
- Sleep disorders

Diagnosis & Testing

Genetic screening is only available for the rarer types of EDS. Diagnosis is through a series of different screening tools:
Personal health history
Family health history
Beighton score of hypermobility - a nine point scale to test extensive range of motion of joints throughout the body
Genetic blood tests - rarer types of EDS, currently no genetic testing for hEDS (most common type)
Echocardiogram
Skin biopsy (evaluate condition of collagen)

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