

Disease Process	Symptom	I have this	Year Started	For Clinician
EDS	Skin hyperextensibility			Test for hEDS
	Soft, velvety skin			using 2018 Ehlers-Danlos Society diagnostic
	Atrophic scars (cigarette-paper scars)			criteria sheet
	Easy bruising			
	Joint hypermobility			
	Repetitive subluxations			
	Repetitive non traumatic joint dislocations			]
	Repetitive sprains			]
	Generalized weakness			]
	Joint swelling			1
	Premature osteoarthritis			]
	Clumsiness			1
	Chronic joint pain			1
	Stretch marks			
	Dental crowding or used a palate expander			
	Recurrent or multiple abdominal hernias			1
	Aortic root dilation			7
History of	GYN: Cervical insufficiency			Test for hEDS
	GYN: Premature rupture of membranes			1
	GYN: Vaginal tears or lacerations			1
	Wound dehiscence			1
	Incisional hernia			
	Mitral valve prolapse			
	Tricuspid valve prolapse			7
	Pelvic floor, rectal, and/or uterine prolapse in children, men, or never pregnant women without other predisposing condition			
	Recurrent rectal prolapse in early childhood			



				013.408.88431	
Disease Process	Symptom	I have this	Year Started	For Clinician	
	Foot deformities such as congenital club foot or pes planus				
Mast Cell Activation Syndrome	Chronic hives			Allergist referral to rule out	
	Flushing			mastocytosis	
	Wheezing				
	Nausea				
	Vomiting				
	Throat swelling				
	Severe itching				
	Nasal stuffiness				
	Anaphylaxis				
Postural Orthostatic	Low blood pressure when standing			Need tilt table testing or 10 min stand test/ could refer to Cardiology	
Tachycardia Syndrome	Positional changes cause dizziness				
	Rapid heart rate upon standing				
	Lightheadedness				
	Exercise intolerance				
	Passing out				
	Tremor				
Gastroparesis	Nausea			Need appropriate	
	Vomiting			GI workup and gastric emptying study	
	Feeling fullness fast			- Study	
	Early feeling of fullness after eating				
	Bloating				
	Upper abdominal pain				
	Weight loss				
ADHD	Inattention (Forgetfulness, distractibility, difficulty listening)			Do ADHD testing Medications as	
	Temporary hyperfocus for highly salient tasks, but lack of attention control when required for daily life activities			appropriate	



		1	1	615.468.8849 Fa
Disease Process	Symptom	I have this	Year Started	For Clinician
	Hyperactivity (Restlessness, fidgeting, rocking, or tapping, pacing, talking too much and too loud)			
	Impulsivity (Acting without thinking, impatience and difficulty waiting turn, interrupting others)			
	Emotional dysregulation(mood wings, irritability, emotional impulsivity, anger outburstS)			
Autism	Family history of: autism spectrum disorders or other developmental disorders			Refer out appropriately for
	Limited eye contact			autism diagnosis
	Delayed speech			
	Stereotypies (repetitive, nonfunctional, atypical behaviors such as hand flapping, rocking, twirling, and finger movements)			
Clinician Associated Traumatization	How many providers have you sought care from without empathy or a solution?			Do PTSD testing Refer out for trauma therapy if positive
	Do you feel like you've been medically gaslit?			
	Do you feel like you've experienced trauma from such experiences?			
	Do you have anxiety, easily startle responses or, avoid going to the doctor as a result?			
Vascular EDS	Skin is thin and transparent with venous pattern visible over chest, abdomen, and extremities			Genetic testing indicated; refer to genetics
	Family history of vascular EDS			
	Family history of arterial rupture or dissection at age < 40 years			
	Family history of spontaneous sigmoid colon perforation in absence of diverticular disease or other bowel pathology			
	Family history of uterine rupture during third trimester in absence of previous c-section and/or severe peripartum perineum tears			
	Family history of carotid-cavernous sinus fistula in absence of trauma			
	Bruising unrelated to identified trauma and/or in unusual locations such as cheeks and back			



Disease Process	Symptom	I have this	Year Started	For Clinician
	Spontaneous pneumothorax			
	Premature aging of the skin			
	Talipes equinovarus (club foot)			
	Congenital hip dislocation			
	Hypermobility of small joints			
	Tendon and muscle rupture			
	Keratoconus			
	Gingival recession and gingival fragility			
	Early onset varicose veins (age < 30 years and nulliparous if female)			
	Arterial rupture or dissection at age < 40 years			
	Unexplained sigmoidal colon rupture			1
Other concerns	Dislocation of the ocular lens			Concern for Marfans
	Hearing loss			Concern for Stickler syndrome
	Short stature			Refer to genetics
When was your last cardiac echo?				EDS patients need cardiac echo q3-4 years

Genetically Characterized Forms of EDS/Reasons to Genetics Test			
Disease Process	Symptom	I have this	
Classical like	Absence of atrophic scarring but still has soft, velvety skin and skin hyperextensibility		
	Leg swelling		
	Muscle weakness		
	Neuropathy		
	Muscle atrophy		
	Family history of classical like EDS		



	015.11	58.8849 Fax
Classical	Molluscoid pseudotumors (fleshy lesions associated with scars at pressure points)	
	Subcutaneous spheroids (small, palpable, spherical hard bodies, commonly mobile, located on forearms and shins, may be calcified and detectable by imaging)	
	Family history of classical EDS	
Cardiac Valvular	Family history of Cardiac Valvular EDS	
	Aortic or mitral valve severe issues	
	Inguinal hernia	
	Chest wall deformity	
Arthrochalasia EDS	Congenital bilateral hip dislocation	
	Kyphoscoliosis	
	Osteopenia	
	Family history of arthrochalasia EDS	
Dermatosparaxis EDS	Family history of Dermatosparaxis EDS	`
	Congenital or postnatal skin tears	
	Short limbs	
	Redundant, lax skin with excessive folding at the wrists and ankles	
	Delayed motor development	
	Bladder rupture, diaphragmatic rupture, or rectal prolapse	
	Hirsutism (abnormal hair growth)	
	Cross eyed	
	Myopia and astigmatism	
Kyphoscoliotic EDS	Family history of Kyphoscoliotic EDS	
	Congenital muscle hypotonia (floppy infant)	
	Congenital or early onset kyphoscoliosis	
	Osteopenia/osteoporosis	
	Blue sclera	
	Chest wall deformity	
	Club foot	



615.468		
	Myopia and hypermetropia	
	Scleral and ocular fragility or rupture	
	Microcornea	
	Congenital hearing impairment	
	Follicular hyperkeratosis	
	Muscle atrophy	
	Bladder diverticula	
Brittle cornea syndrome	Thin cornea with or without rupture	
	Early onset progressive keratoconus	
	Early onset progressive keratoglobus	
	Blue sclera	
	Minor criteria	
	Enucleation or corneal scarring as a result of previous rupture	
	Progressive loss of corneal stromal depth, particularly in central cornea	
	High myopia with normal or moderately Increased axial length	
	Retinal detachment	
	Deafness	
	Hypercompliant tympanic membranes	
	Developmental dysplasia of hip	
	Hypotonia in infancy (typically mild)	
	Scoliosis	
	Family history of Brittle cornea syndrome	
	Mild contractures of fingers	
Spondylodysplastic EDS	Family history of Spondylodysplastic EDS	
	Short stature	
	Muscle hypotonia (ranging from mild later-onset to severe congenital)	
	Bowing of limbs	
	Osteopenia	
	Delayed cognitive development	



CEITTC	013.40	8.8849 Fax
	Radioulnar synostosis	
	Clouded cornea	
	Tooth discoloration or dysplastic teeth	
	Osteoporosis with multiple Spontaneous fractures	
	Ascending aortic aneurysm	
	Lung hypoplasia or restrictive lung Disease	
	Blue sclera	
Musculocontractural EDS	Family history of Musculocontractural EDS	
	Multiple congenital contractures	
	Chest deformity	
	Scoliosis or kyphoscoliosis	
	Pneumothorax/pneumohemothorax	
	Cross eyed	
	Myopia or astigmatism	
	Glaucoma/elevated intraocular pressure	
Myopathic EDS	Family history of myopathic EDS	
	Congenital muscle hypotonia and/or Muscle atrophy that improves with age	
	Joint contractures	
	Motor development delay	
	Myopathy on muscle biopsy	
Periodontal EDS	Family history of Periodontal EDS	
	Severe and intractable periodontitis during childhood or adolescence	
	Detached gingiva	
	Pretibial plaques	
	Hernias	