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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 or refer to genetics
	Easy bruising			Guidelines to
	Joint hypermobility			change in 2026.
	Repetitive subluxations			
	Repetitive non traumatic joint dislocations			
	Repetitive sprains			
	Generalized weakness			
	Joint swelling			
	Premature osteoarthritis			
	Clumsiness			
	Chronic joint pain			
	Stretch marks			
	Dental crowding or used a palate expander			
	Recurrent or multiple abdominal hernias			
	Aortic root dilation			
History of	GYN: Cervical insufficiency			Test for hEDS
	GYN: Premature rupture of membranes			
	GYN: Vaginal tears or lacerations			
	Wound dehiscence			
	Incisional hernia			
	Mitral valve prolapse			
	Tricuspid valve prolapse			



Disease Process	Symptom	I have this	Year Started	For Clinician
	Pelvic floor, rectal, and/or uterine prolapse in children, men, or never pregnant women without other predisposing condition			
	Recurrent rectal prolapse in early childhood			
	Foot deformities such as congenital club foot or pes planus			
Mast Cell Activation	Chronic hives			Allergist referral
Syndrome	Flushing			to rule out mastocytosis
	Wheezing			
	Nausea			
	Vomiting			
	Throat swelling			
	Severe itching			
	Nasal stuffiness			
	Anaphylaxis			
Postural Orthostatic Tachycardia Syndrome	Low blood pressure when standing			Need tilt table testing or 10 min
Tactiycardia Syndrome	Positional changes cause dizziness			stand test/ could refer to
	Rapid heart rate upon standing			Cardiology
	Lightheadedness			
	Exercise intolerance			
	Passing out			
	Tremors			
Gastroparesis	Nausea			Need appropriate GI workup and
	Vomiting			gastric emptying study
	Feeling fullness fast			study
	Early feeling of fullness after eating			
	Bloating			
	Upper abdominal pain			
	Weight loss			



Disease Process	Symptom	I have this	Year Started	For Clinician
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
	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?			
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 card	liac echo?			EDS patients need cardiac echo q3-4 years



Red Flags	
Need for immediate genetic testing or genetics referral	
Hypermobility plus one of the following:	
Sign/Symptom	I have this
Very thin atrophic scars	
Extreme skin extensibility	
Severe kypho (scoliosis) requiring corset or surgery	
Severe pectus deformity	
Contractures	
Repetitive bone fractures and congenital abnormalities like b/l hip dislocation or club feet	
Dilation or dissection of the thoracic aorta	
Arterial aneurysms/dissections/ruptures	
Severe unexplained bleeding	
Arterial tortuosity	
Unexplained tears or ruptures to hollow organs	
Uterine rupture	
Eye lens subluxation, retinal detachment, keratoconus	
Abnormally tall or short (2SD)	
Short limbs arachnodactyly or bifid uvula	
Spontaneous or repeated pneumothorax	
First or second degree relative with sudden premature death <50 yrs unexplained or d/t vascular rupture, bleeding, or organ rupture	
Family member with proven mutation for hereditary connective tissue disease or other hereditary syndrome	





Genetically Characterized Forms of EDS (Reasons to Genetic Test or Refer Out)

Disease Process	Symptom Actually Diagnosed	I have this
Vascular EDS	Skin is thin and transparent with venous pattern visible over chest, abdomen, and extremities	
	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	
	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	
Classical like	Absence of atrophic scarring but still has soft, velvety skin and skin hyperextensibility	
	Leg swelling	
	Muscle weakness	
	Neuropathy	



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	Muscle atrophy	
	Family history of classical like EDS	
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, astigmatism	
Kyphoscoliotic EDS	Family history of Kyphoscoliotic EDS	
	Congenital muscle hypotonia (floppy infant)	
	Congenital or early onset kyphoscoliosis	
	Osteopenia/osteoporosis	
	Blue sclera	



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	Chest wall deformity	
	Club foot	
	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	



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	Muscle hypotonia (ranging from mild later-onset to severe congenital)	
	Bowing of limbs	
	Osteopenia	
	Delayed cognitive development	
	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	



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	Pretibial plaques	
	Hernias	

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