

Long COVID & Post-Viral Syndromes ECHO

Anatomical Neurological Complications in Long-COVID and ME/CFS



Brayden Yellman, MD



Theresa Dowell, FNP PT

January 18, 2024



Patient cases are shared in this session for educational purposes. In some cases, the information does not relate to an individual, and instead represents a compilation of disease presentation.

In cases involving individual patient information, the patients have authorized the discussion of their case in this setting.

No Disclosures

Bateman Horne Center is a **Non-Profit Center of Excellence** dedicated to furthering clinical care, research, and patient and provider education regarding ME/CFS, Post-Acute Sequelae of COVID-19 (PASC), and related comorbidities (including connective tissue disorders like Ehlers Danlos Syndrome)

Neurological and Spinal Manifestations of EDS Syndromes, ME/CFS, Long-COVID

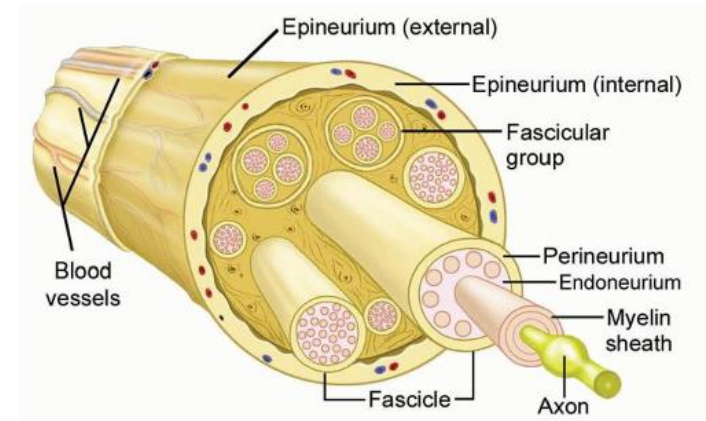
- Headache
- Migraine
- Idiopathic Intracranial Hypertension (IIH)
- Chiari 1 Malformations
- **Craniocervical Instability (CCI)**
- **Atlantoaxial Instability (AAI)**
- Spinal Kyphosis and Instability
- **Acquired/Occult Tethered Cord Syndrome**
- Dystonias and Other Movement Disorders
- Tarlov Cyst Syndrome

Abnormal neuromuscular features

- Myalgia
- Nocturnal Muscle Cramping
- Progressive Muscle Weakness
- Hypotonia
- Poorly Developed Muscles
- Scapular Winging

Neurological and Spinal Manifestations of EDS Syndromes, ME/CFS, Long-COVID:

- Incompetent connective tissues may result in laxity of ligaments within the axial skeleton, peripheral nerve sheaths, and even architecture of myoneural and muscular endplates
- Neurological manifestations may arise from associated weakness of the ligaments of the craniocervical junction and spine, from early disc degeneration, and from weakness of the epineurium and perineurium surrounding peripheral nerves
- Ligamentous laxity, in particular, leads to nerve structure entrapment, deformation, of biophysical deformative stresses
- These stresses may then contribute to secondary altered gene expression, cellular function, neuronal function, and phenotypic expression



Themes, UFO. "Surgical Treatment of Nerve Tumors in the Distal Upper Extremity." *Musculoskeletal Key*, 22 July 2016, musculoskeletalkey.com/surgical-treatment-of-nerve-tumors-in-the-distal-upper-extremity/.

Disclaimer:

- Authors of this study represent a working group within the International Consortium on the Ehlers-Danlos Syndromes
- Consensus Criteria and clinical practice guidelines will still require stronger epidemiological and pathophysiological evidence in the future

Craniocervical Instability (CCI)/Atlantoaxial Instability (AAI) (M53.2X2)

- Increasing recognition of the formation of **axon retraction balls/bulbs** as a result of stretching or deformative stress injury upon neurons
- Similar to findings seen in diffuse axonal injury of the brain
- Stretching of neurons causes pathological calcium influx, altered gene expression, even apoptosis

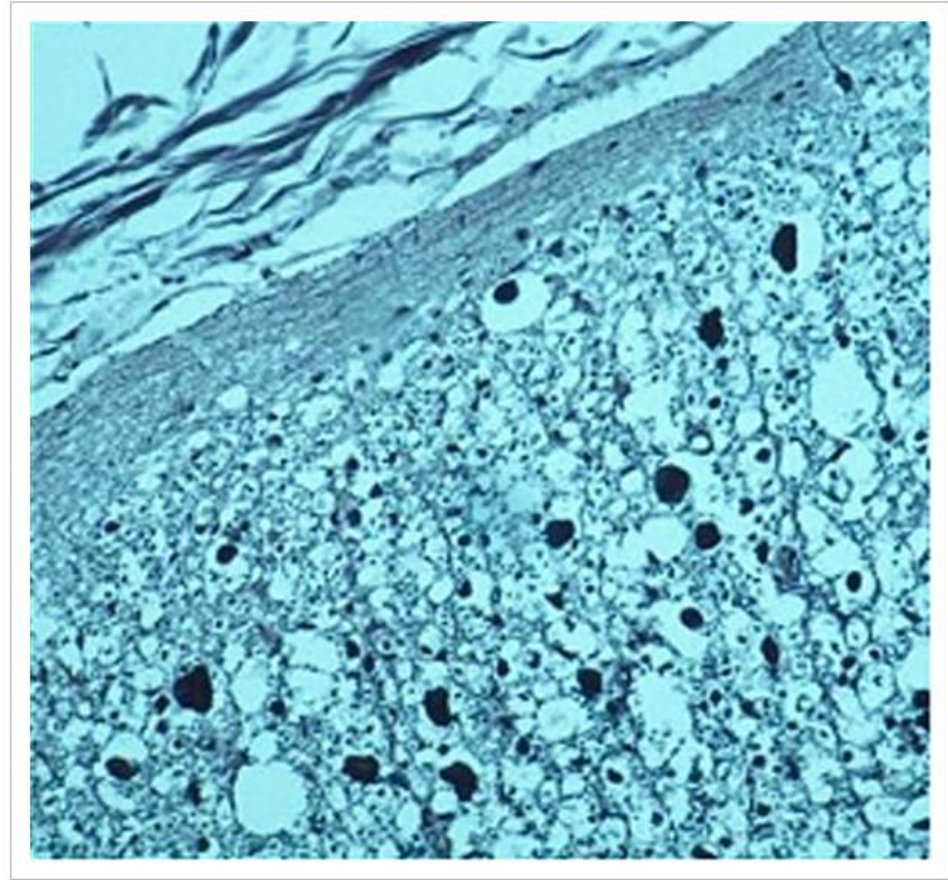
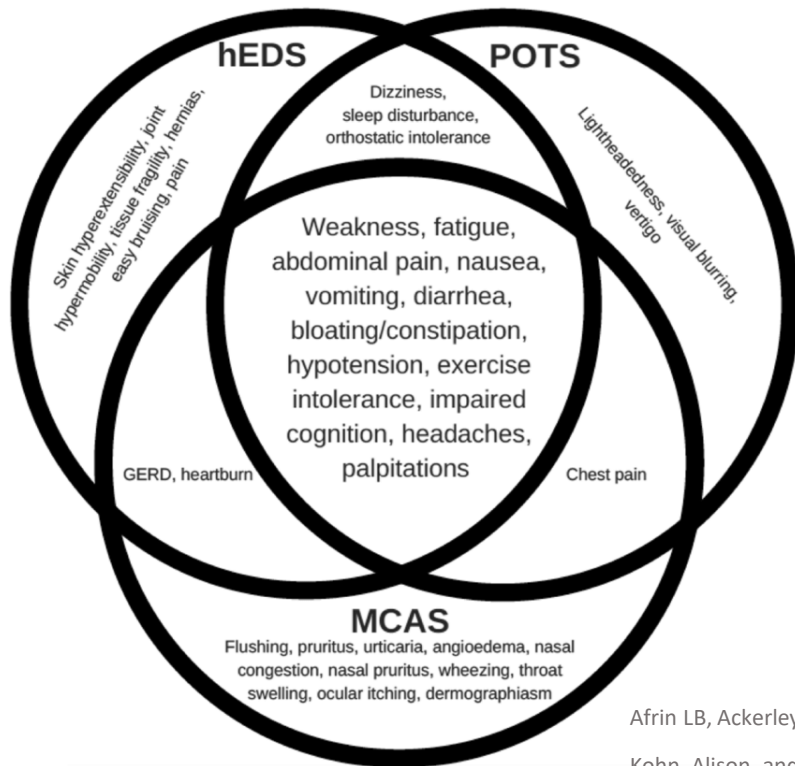


Figure 2

[Open in figure viewer](#) | [Download PowerPoint](#)

Axon retraction bulbs in the upper spinal cord, from cadaveric studies of subjects with basilar invagination (Microscopic photograph (x500), axial section of the dorsal column at the C2 level. Silver stain).

Mast Cell Activation Syndrome (MCAS)/ Mast Cell Activation Disorder (MCAD) (D89.4)



- Nearly 1 in 3 patients with MCAS had a comorbid diagnosis of hEDS in a sample of 37,665 patients diagnosed with either disorder
- In one study, 66% of patients with POTS and EDS also met symptoms for MCAS

Afrin LB, Ackerley MB, Bluestein LS, et al. Diagnosis of mast cell activation syndrome: a global “consensus-2”. *Diagnosis (Berl)*. 2020:dex-2020-0005.10.1515/dx-20200005.

Kohn, Alison, and Christopher Chang. “The relationship between Hypermobile Ehlers-Danlos syndrome (heds), postural orthostatic tachycardia syndrome (POTS), and mast cell activation syndrome (MCAS).” *Clinical Reviews in Allergy & Immunology*, vol. 58, no. 3, 2019, pp. 273–297, <https://doi.org/10.1007/s12016-019-08755-8>.

Lyons JL, Yu X, Hughes JD, Le QT, Jamil A, Bai Y, et al. Elevated basal serum tryptase identifies a multisystem disorder associated with increased TPSAB1 copy number. *Nat Genet*. 2016;48:1564–1569. doi: 10.1038/ng.3696.

Monaco, Ashley, et al. “Association of Mast-cell-related conditions with hypermobile syndromes: A review of the literature.” *Immunologic Research*, vol. 70, no. 4, 2022, pp. 419–431, <https://doi.org/10.1007/s12026-022-09280-1>.

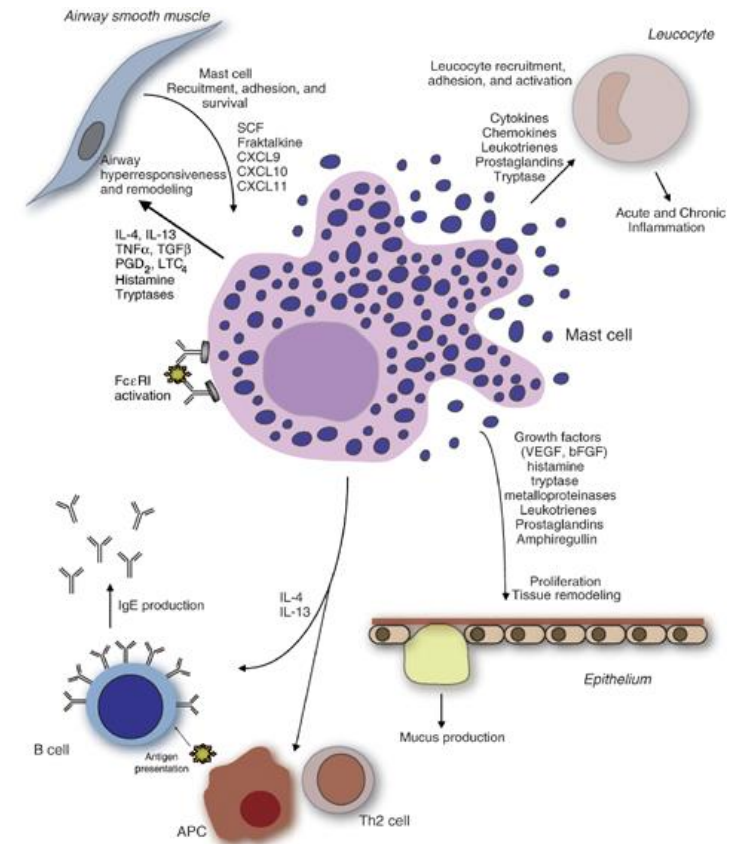
Seneviratne SL, Maitland A, Afrin L. 2017. Mast cell disorders in Ehlers–Danlos syndrome. *Am J Med Genet Part C Semin Med Genet* 175C:226–236.

Mast Cell Activation Syndrome (MCAS)/ Mast Cell Activation Disorder (MCAD) (D89.4)

- When mast cells are “activated,” they release a collection of inflammatory mediators, cytokines, and proteases, with histamine, tryptase, and leukotrienes being the most well-known of these
- Mast cells are normally activated in the presence of a type of antibodies known as IgE antibodies, as well as several other types of immune system triggers

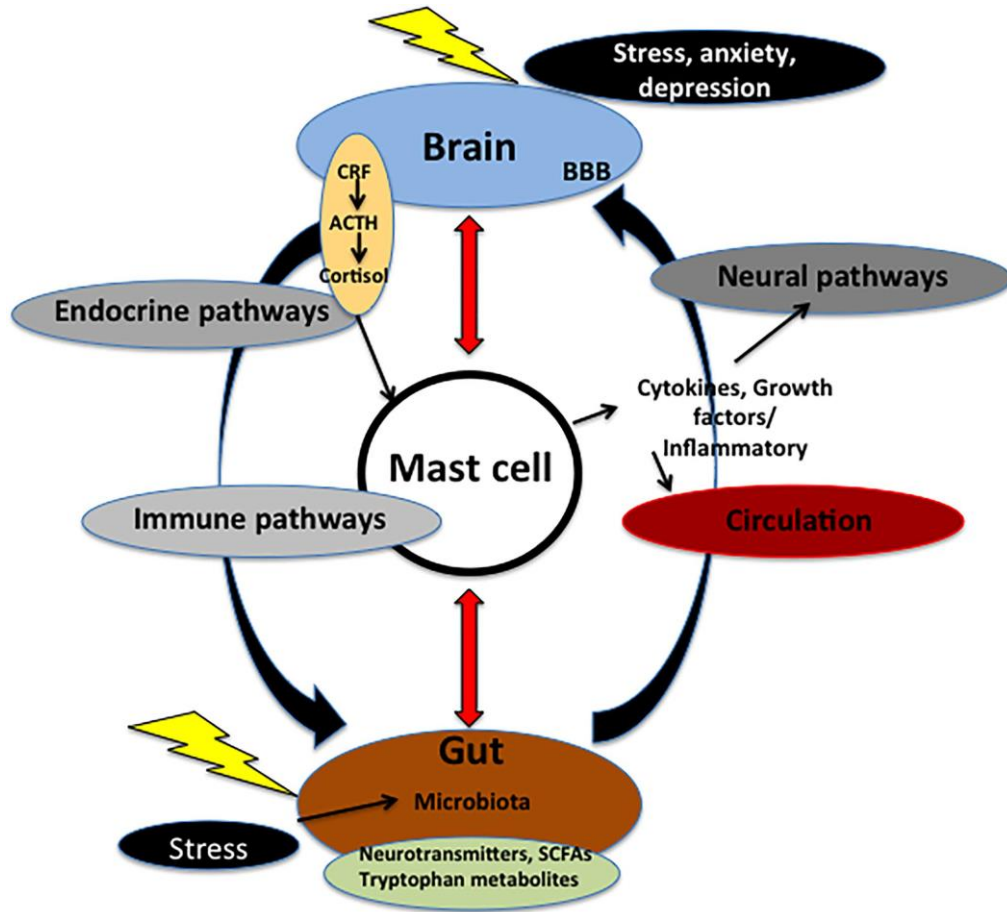
“Mast Cell Activation Syndrome: AAAAI.” The American Academy of Allergy, Asthma, & Immunology, www.aaaai.org/conditions-and-treatments/related-conditions/mcas

Mast Cell Activation Syndrome: A review. Frieri M., Patel R., Celestin J. *Curr Allergy Asthma Rep.* 2013 Feb;13(1):27-32. doi: 10.1007/s11882-012-0322-z.



Clinical & Experimental Allergy, Volume: 38, Issue: 1, Pages: 4-18, First published: 21 November 2007, DOI: (10.1111/j.1365-2222.2007.02886.x)

Mast Cell Activation Syndrome (MCAS)/ Mast Cell Activation Disorder (MCAD) (D89.4)

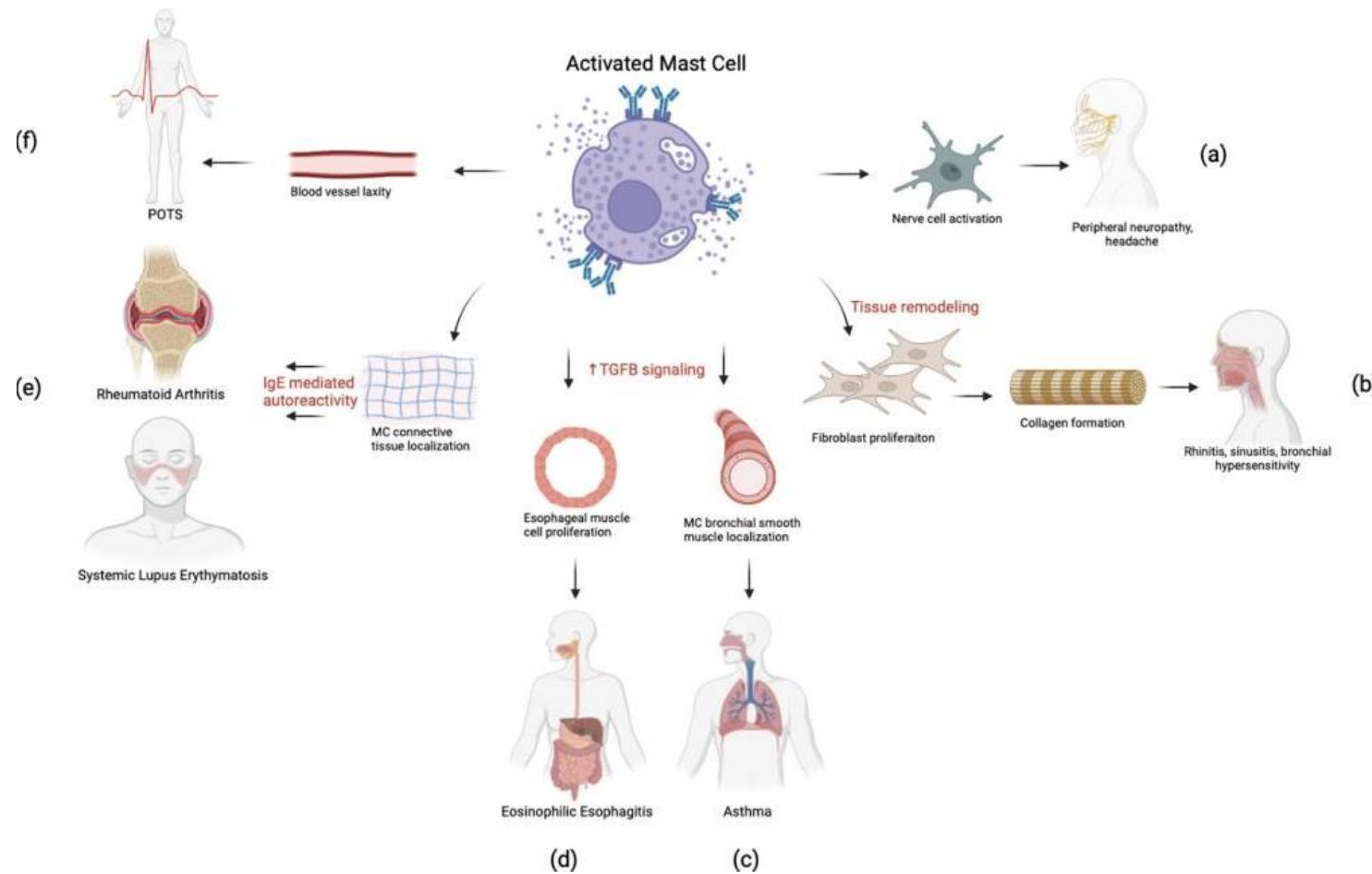


- Activated mast cells may also send distress signals, through the nervous system and immune system, to other areas of the body, alerting additional mast cells to activate as well

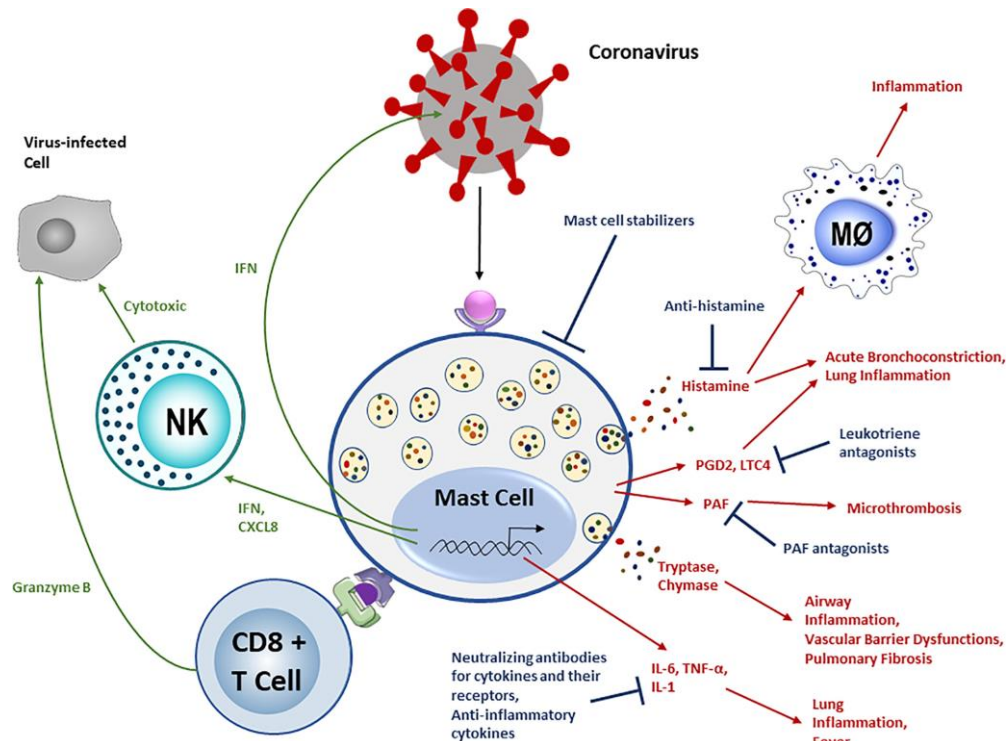
Mast Cell Cytokine Mediators

Mast cells produce inflammatory changes in connective tissues, affecting multiple organ systems:

- a.) Localized to peripheral nerve epineurium, perineurium, and endoneurium, releasing mediators that may active nociceptive symptoms like peripheral neuropathy, headache, small fiber polyneuropathy
- b.) MC cytokines can lead to dysfunctional fibroblast proliferation in nasal and bronchial tissue, associated rhinitis and sinusitis
- c.) MC-induced TGF- β upregulation in bronchial smooth muscle can modify matrix proteins of bronchial parenchyma, contribute to tissue damage and asthma
- d.) TGF- β upregulation in esophageal tissue causing proliferation and smooth muscle contraction (dysphonia, dysphagia, globus, eosinophilic esophagitis)
- e.) MC's in local connective tissue cause microenvironmental changes to the extracellular matrix, inducing IgE-mediated autoreactivity, which may play a role in rheumatological conditions
- e.) Laxity of blood vessels with pooling of blood in the extremities (POTS, dysautonomia, ME/CFS, PASC)



Mast Cell Activation Syndrome & COVID-19



- Mast cells may serve as hosts for SARS-CoV-2 by expressing ACE2, an important receptor for this virus upon host cells
- Upon stimulation by SARS-CoV-2, mast cells rapidly secrete preformed granules as well as cytokines and chemokines within 6-24 hours

Lam, Hiu Yan, et al. "Mast Cells: Therapeutic targets for covid-19 and beyond." *IUBMB Life*, vol. 73, no. 11, 2021, pp. 1278–1292, <https://doi.org/10.1002/iub.2552>.

Mathias K, Mantha A, Mathias L, et al. POS1366 The Relationship of Mast Cell Activation Syndrome and Hypermobile Ehlers-Danlos Syndrome in Hospitalized Patients in the United States. *Ann Rheum Dis*. 2021;80:965. doi: 10.1136/annrheumdis-2020-219825.

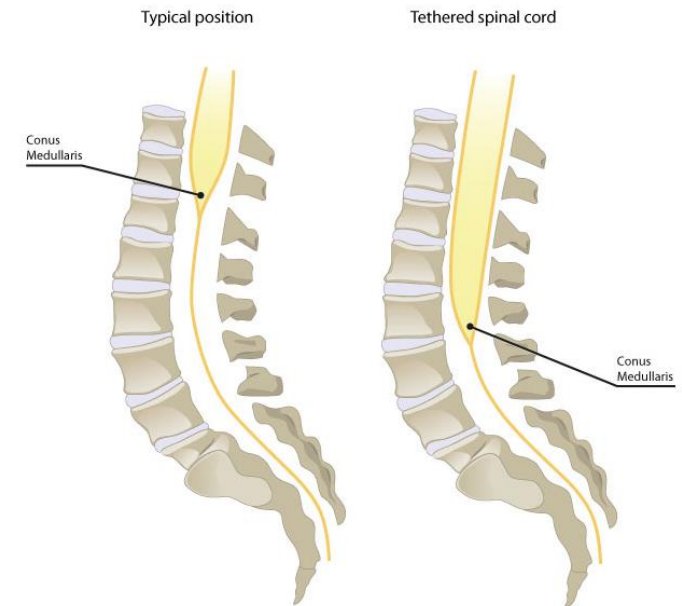
Monaco, Ashley, et al. "Association of Mast-cell-related conditions with hypermobile syndromes: A review of the literature." *Immunologic Research*, vol. 70, no. 4, 2022, pp. 419–431, <https://doi.org/10.1007/s12026-022-09280-1>.

Theoharides TC. Potential association of mast cells with coronavirus disease. *Ann Allergy Asthma Immunol*. 2021;126(3):217–218. doi: 10.1016/j.anai.2020.11.003.

Valent P, Akin C, Bonadonna P, et al. Risk and management of patients with mastocytosis and MCAS in the SARS-CoV-2 (COVID-19) pandemic: expert opinions. *J Allergy Clin Immunol*. 2020;146(2):300–306. doi: 10.1916/j.jaci.2020.06.009.

Acquired/Occult Tethered Cord Syndrome (G95.89)

- Anatomical restriction of the normal movement of the spinal cord via the filum terminale “tightening” or “tethering” abnormally
- A healthy filum is a fibrous, collagenous, and elastic band connecting the conus medullaris to the dural sac at the s2 level
- Filum appears to be morphologically altered with fatty tissue, dysplastic axons (“nerve twigs”), fat and vascular lacunes, or even “congested” veins
- Pathology thought to be from forcible flexion stretching of the spinal cord against the filum causing tissue damage and repair, inflammation (MCAS?), and/or altered gene expression



partnership, London Neurosurgery. “Tethered Cord – Condition and Symptoms - How to Treat.” *London Neurosurgery Partnership - Spine & Neurosurgery*, 28 May 2021, [Inpu.com/tethered-cord-condition-and-symptoms/](https://inpu.com/tethered-cord-condition-and-symptoms/).

Tethered Cord Syndrome: Symptoms (G95.89)

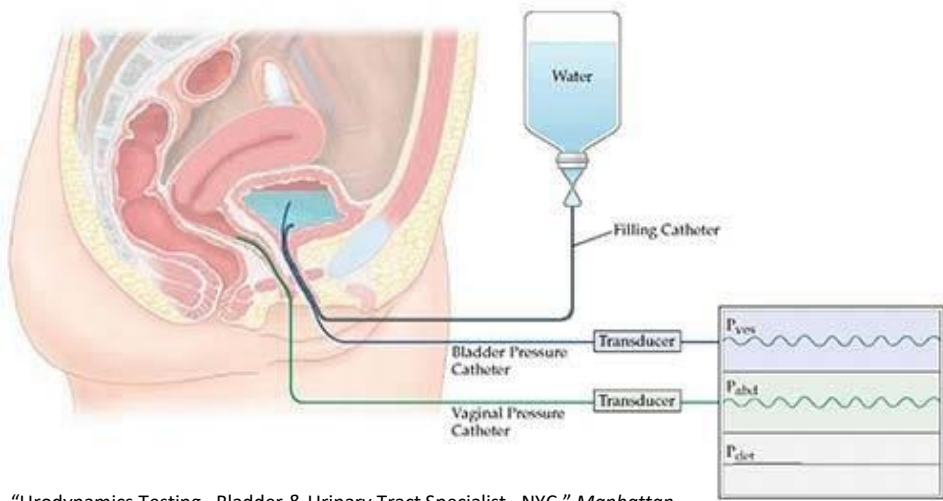
Classic Triad:

- Neurogenic Bladder
- Lower Extremity Weakness and Sensory Loss
- Lower Back Pain



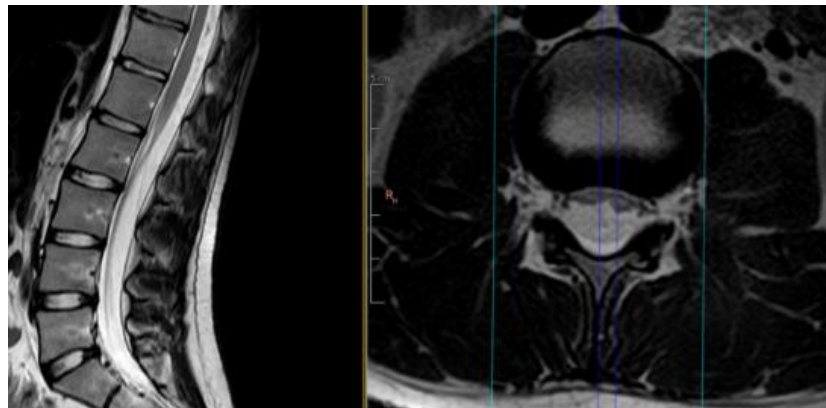
- Unsteady gait
- Loss of lower extremity sensation
- Pain (often migratory) in lower extremities
- Urinary frequency/urgency
- Frequent UTI's
- Dysuria
- Urinary retention
- Gastrointestinal problems/dysfunction
- Lower back pain
- Pulling sensation (brain, upper spine, sacral)
- Suboccipital pain/pressure
- Toe Walking/Inability to Heel-Walk

Tethered Cord Syndrome: Diagnostics (G95.89)



“Urodynamics Testing - Bladder & Urinary Tract Specialist - NYC.” *Manhattan Gynecologists & Best Rated OBGYN Specialists in NYC*, 23 Sept. 2023, www.obgynecologistnyc.com/procedures/urodynamics/.

- **Urodynamic Testing** to evaluate for neurogenic bladder manifestations
- **Somatosensory and Motor Evoked Potentials**
- **3T Prone/Supine L-spine MRI** (specific protocol not done at most imaging centers)

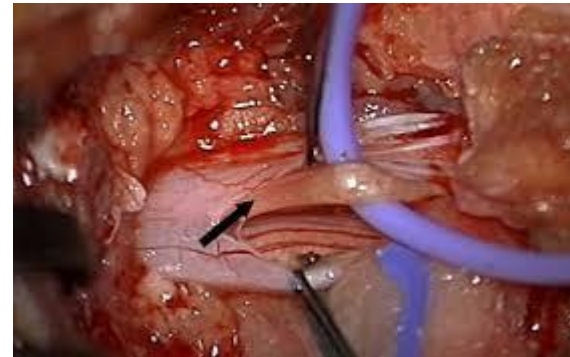
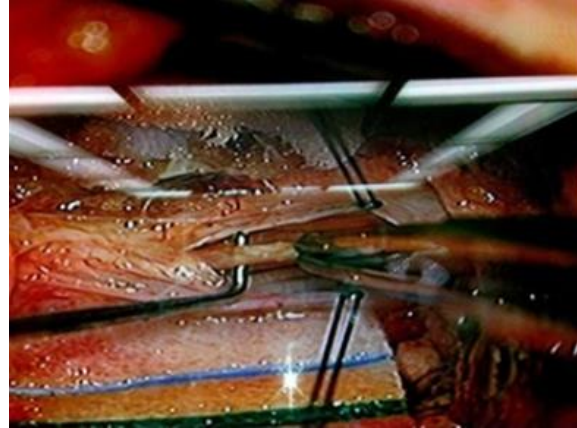


Remember: normal supine MRI usually not adequate for evaluation. Few currently doing appropriate evaluations.



Tethered Cord Syndrome: Treatment (G95.89)

- Surgical detethering is a viable option for those presenting with moderate to severe symptoms and radiographic findings
- Some cases can retether again over time
 - Continued abnormal forces from CCI/AAI?
 - MCAS or other inflammation?
 - Surgical “Gore-Tex” to help prevent retethering

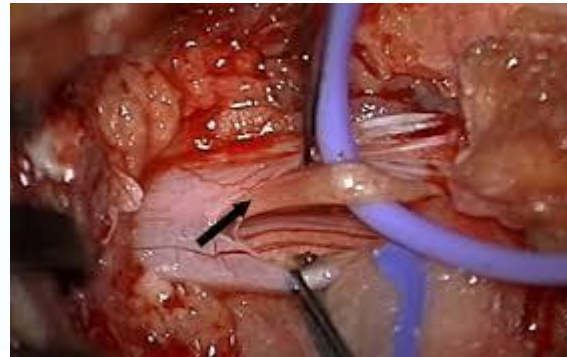


Agarwalla, Pankaj K., et al. “Tethered cord syndrome.” *Neurosurgery Clinics of North America*, vol. 18, no. 3, 2007, pp. 531–547, <https://doi.org/10.1016/j.nec.2007.04.001>.

- The filum terminale could be part of a sensorimotor system involved in spinal alignment, sensing non-physiological stretch forces from excessive spinal movements
- As such, the filum terminale could be acting as a stabilization syndrome in some cases of CCI/AAI
- Surgical detethering could thus expose or exacerbate existing CCI/AAI, but could also allow for improved clinical response to cervical traction

Tethered Cord Syndrome: Treatment (G95.89)

- Surgical detethering is a viable option for those presenting with moderate to severe symptoms and radiographic findings
- Some cases can retether again over time
 - Continued abnormal forces from CCI/AAI?
 - MCAS or other inflammation?
 - Surgical “Gore-Tex” to help prevent retethering



Agarwalla, Pankaj K., et al. “Tethered cord syndrome.” *Neurosurgery Clinics of North America*, vol. 18, no. 3, 2007, pp. 531–547, <https://doi.org/10.1016/j.nec.2007.04.001>.

- The filum terminale could be part of a sensorimotor system involved in spinal alignment, sensing non-physiological stretch forces from excessive spinal movements
- As such, the filum terminale could be acting as a stabilization syndrome in some cases of CCI/AAI
- Surgical detethering could thus expose or exacerbate existing CCI/AAI, but could also allow for improved clinical response to cervical traction

Invisible Bond: Clinical case study on occult tethered cord syndrome"

Theresa Dowell, FNP PT

January 18, 2024



Symptoms of
Occult Tethered
Cord Syndrome
**are often subtle
or absent.**

Image by Freepik.

Chief Complaints

32-year-old female with complaints of fatigue, headaches/migraines, muscle/joint pain, insomnia, dizziness/vertigo, gastrointestinal dysfunction, diffuse pruritis, cognitive impairment and chest pain.

Past Medical History

November 2016

- Onset of sore throat, headaches, photophobia, sound sensitivity, low grade fever, fatigue, and rash.
- One-week later develops dizziness, paresthesia, myalgia, nuchal rigidity, gingivitis, and cognitive impairment.
- Throat culture positive for Strep G infection; treated with seven days of penicillin.

December 2016

- Borderline anemia; treated with iron.
- **Cervical radiculopathy which radiates to right shoulder.**
- **Slow walking triggers lower extremity myalgia.**

January 2017

- Onset orthostatic hypotension, normal EKG
- Onset of insomnia, nausea, loss of appetite, temperature intolerance, **severe leg pain increased with activity, especially walking up stairs.**
- Suspicious for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS).

Past Medical History

February 2017

- MRI of brain and cervical spine unremarkable. Neurology ruled out multiple sclerosis.
- Endocrine testing unremarkable.
- Referred to infectious disease; lumbar puncture yielded unremarkable results.

April 2017

- Epstein Barr Virus lab IgM positive

December 2018

- Walking 3 minutes per day triggers pain.
- Using mobility scooter.
- Working 15 hours per week.

History of Present Illness

Fatigue: Chronic debilitating fatigue. Fatigue is triggered by upright posture and over-exertion. Reports post exertional malaise.

Headaches: Two headaches per weeks. Headaches typically last from 5 hours to 4 days.

Insomnia: Difficulty falling asleep, restless sleep, frequent awakening and difficulty falling back to sleep. Sleep is primarily unrefreshed.

Neurological: Intermittent dizziness and vertigo.

Gastrointestinal: GERD. Denies nausea, abdominal pain and IBS. Increase motion sickness.

Allergies: Pruritus on back and flushing. Reports canker sores.

Neurocognitive: Forgetfulness and difficulty with word finding. Depression and anxiety.

Cardiovascular: Chest pain for one year.

Pain: Migrating, intermittent muscle and joint pain. **Muscle pain is mostly in legs and arms.** Joint pain is primarily in knees, elbow, wrists and fingers. Cervical radiculopathy which radiates to right shoulder. Describes pain as burning, hot, aching and dull.

Physical Examination



- Unremarkable exam
- Did not meet criteria for hypermobile spectrum
- Unremarkable neurological examination
- Deep tendon reflexes symmetrical graded 2/4, negative Romberg.

NASA Lean Test

	Systolic BP	Diastolic BP	Heart Rate
Supine 1 minute	104	70	68
Supine 2 minutes	105	70	71
Standing 0 minute	108	67	73
Standing 1 minutes	115	87	102
Standing 2 minutes	112	94	100
Standing 3 minutes	118	80	118
Standing 4 minutes	92	72	115
Standing 5 minutes	100	75	109

Meets criteria for postural orthostatic tachycardia syndrome (POTS)

Investigations

- Borreliosis- negative
- Mast cell mediators- unremarkable
- Immunoglobulins- unremarkable
- Lymphocyte subset panel- slightly low white blood cells
- Endocrinological, rheumatological labs unremarkable
- Infectious disease- Epstein Barr virus (EBV) IgM, Early Antigen positive

Treatment Plan

- Treat postural orthostatic tachycardia syndrome (confirmed by neurology) with pyridostigmine bromide.
- Treat EBV with valacyclovir.
- Treat sleep, fatigue, pruritis, pain, headaches, gastrointestinal complaints, neurocognitive dysfunction
- Rule out cerebral spinal fluid leak



Worsening Symptoms

- Becomes bedbound secondary to **upper and lower extremity pain**. Onset of pain in lower lumbar spine. Maintains reclined position with pillows under legs to decrease pain.
- Cervical radiculopathy which radiates to right shoulder.
- Worsening fatigue, cognitive function, insomnia, headaches, POTS.
- **Onset of urinary frequency (every 45 minutes)**, residual voiding.

Suspicious for Tethered Cord

- Consult 12/2019 with neurosurgeon for cranial cervical instability; surgeon suspects TC.
- Consult 9/2020 with second neurosurgeon; diagnosed with TC:
 - **Upper and lower extremity pain**
 - **Urinary frequency, residual voiding, urodynamic testing**
 - Neurological exam abnormalities
 - **Walking trigger pains**
 - Lumbar MRI, low lying conus
- Surgery 11/2020. (Onset of illness 11/2016; initial evaluation 2/2019)

Bowel and Bladder

- Bowel incontinence, constipation (50/50)
- Neurogenic bladder, urinary frequency, urgency, retention, frequent urinary tract infections (3 per year)

Neurologic

- Spasticity, hyperreflexia, clonus



Orthopedic

- Toe walking, club feet, leg deformities, scoliosis, kyphosis
- Pelvic, lumbar, and lower extremities aches, burns, fatigue, heavy, stiff, tightness
- Pain migrates (no radiating)
- Growing pains
- Increased pain when walking on incline or stairs

Consensus Statement proposed at the Chiari Syringomyelia Foundation Colloquium New Orleans 2015

Tethered cord syndrome:

- Progressive weakness and sensory impairment of the lower extremities, back and leg pain, neurogenic bladder (and bowel symptoms) are elements that should prompt consideration of Tethered Cord syndrome
- **Tethered cord syndrome is a clinical diagnosis**, based upon complete history, thorough neurological examination and thorough review of urodynamic and radiological findings, preferably in a multispecialty team
- The diagnosis of tethered cord syndrome should consider coexisting co-morbidities that may confound the clinical diagnosis, i.e. disorders of the craniocervical junction, the cervical, thoracic and lumbar spine, such as Chiari malformation, compression of the spinal cord by stenosis, disc or other pathologies, spinal deformity or instability, genetic disorders, and medical disorders such as Multiple sclerosis, diabetes mellitus
- The diagnosis of tethered cord syndrome requires:
 - The patient is moderately or severely disabled as a result of the following symptoms that may present in combination or in isolation
 - **Symptoms of**
 - **Low back pain, and**
 - **Leg pain and weakness and sensory deficits, and**
 - **Urinary incontinence or bowel dysfunction**
 - **Findings on examination of**
 - **Leg weakness, and**
 - **Sensory impairment in the lower extremity/ies**
 - **Diagnosis of neurogenic bladder preferably confirmed by urodynamic testing**
 - **A radiological assessment with is suggestive of tethered cord syndrome by ruling out other likely causes of the above findings**
 - **A reasonable assessment that he above findings are not part of other medical illness (as reviewed under 3.)**
 - Other clinical findings should be present, including some of the following: sacral dimple or neurocutaneous markers, stretch signs (stretching cauda equine or cord increases pain and sensory deficits), **flat feet, hammer toes, hyper-reflexia of the lower extremities, changes in tone of the lower extremities, foot and knee varus and valgus deformities and/or scoliosis**
 - Radiological findings may include some of the following: low lying conus, scoliosis, syringohydromyelia, spina bifida occulta, fatty or thickened filum (>2mm), obvious tethering of the neural elements that may be assess with a prone and supine lumbar MRI to assess conus movement and movement of the cauda equina

CLINICAL PEARLS



1. Musculoskeletal:
 1. Hypermobile spectrum or hypermobile Ehlers Danlos Syndrome
 2. Toe walker, in toeing, toe curling as a child
 3. Scoliosis
 4. Growing pains
 5. Pulling sensation on neck
2. Lumbar and lower extremity:
 1. Pain described as ache, burn, stiff, tight
 2. Pain increased when walking; especially up stairs and inclines
 3. Places pillows under knees and/or sleeps with knees bent
 4. **Pain with forward trunk flexion**
3. Bowel and bladder:
 1. Constipation
 2. Urinary frequency, residual void, urinary tract infections, urgency
4. Neurological:
 1. Hyper reflexive deep tendon reflexes
 2. Clonus at the ankle, patella, wrist, biceps brachii
 3. Tremors or spasms in upper and lower extremities
 4. Antalgic or spastic gait
5. **Worsening of symptoms**
6. Comorbid mast cell activation syndrome, postural tachycardia syndrome, hypermobile Ehlers Danlos syndrome
7. Non-responders to ME/CFS treatments

Physical Examination

- Spine observed and palpated for abnormalities and scoliosis.
- Assess for hypermobility using the Beighton Score.
- Lumbosacral spine and coccygeal region inspected for cutaneous manifestations (hairy patch, hemangioma, dimple, lumbosacral mass, caudal tail).
- Neurological examine which includes pin prick and light touch in each dermatome.
- Reflexes in upper and lower extremities.
- Manual muscle strength testing.
- Gait assessment.

THE BEIGHTON SCORING SYSTEM

Measuring joint hypermobility

A. 5th FINGER / 'PINKIES'

Test **both sides**. Rest palm of the hand and forearm a **flat surface** with palm side down and fingers out straight.

Can the **fifth finger** be bent/lifted upwards at the knuckle to go back **beyond 90 degrees**?

If yes, add **one point** for each hand.



B. THUMBS

Test **both sides**: With the arm out straight, the palm facing down, and the wrist then fully bent downward, can the thumb be pushed back to touch the forearm?

If yes, add **one point** for each thumb.



C. ELBOWS

Test **both sides**: With arms outstretched and palms facing upwards, does the elbow extend (bend too far) upwards **more than an extra 10 degrees** beyond a normal outstretched position?

If yes, add **one point** for each side.



D. KNEES

Test **both sides**: While standing, with knees locked (bent backwards as far as possible), does the lower part of either leg extend **more than 10 degrees forward**?

If yes, add **one point** for each side.

E. SPINE

Bend forward, can you place the palms of your hands **flat on the floor in front of your feet** without bending your knees?

If yes, add **one point**.

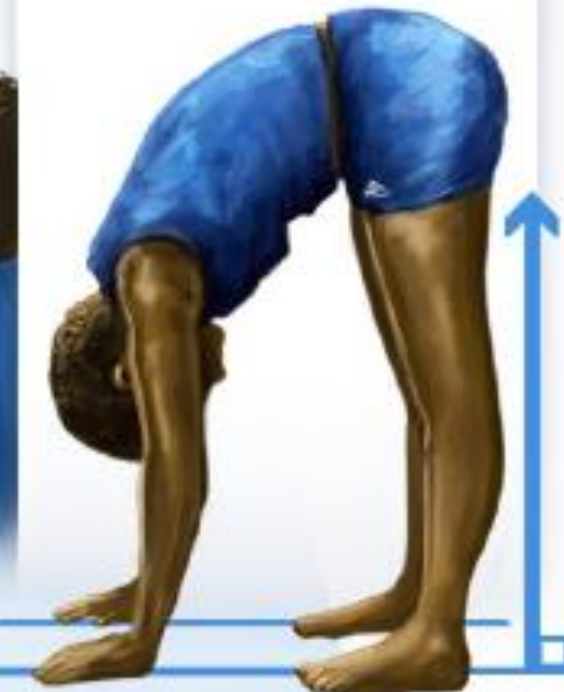




Image by Freepik

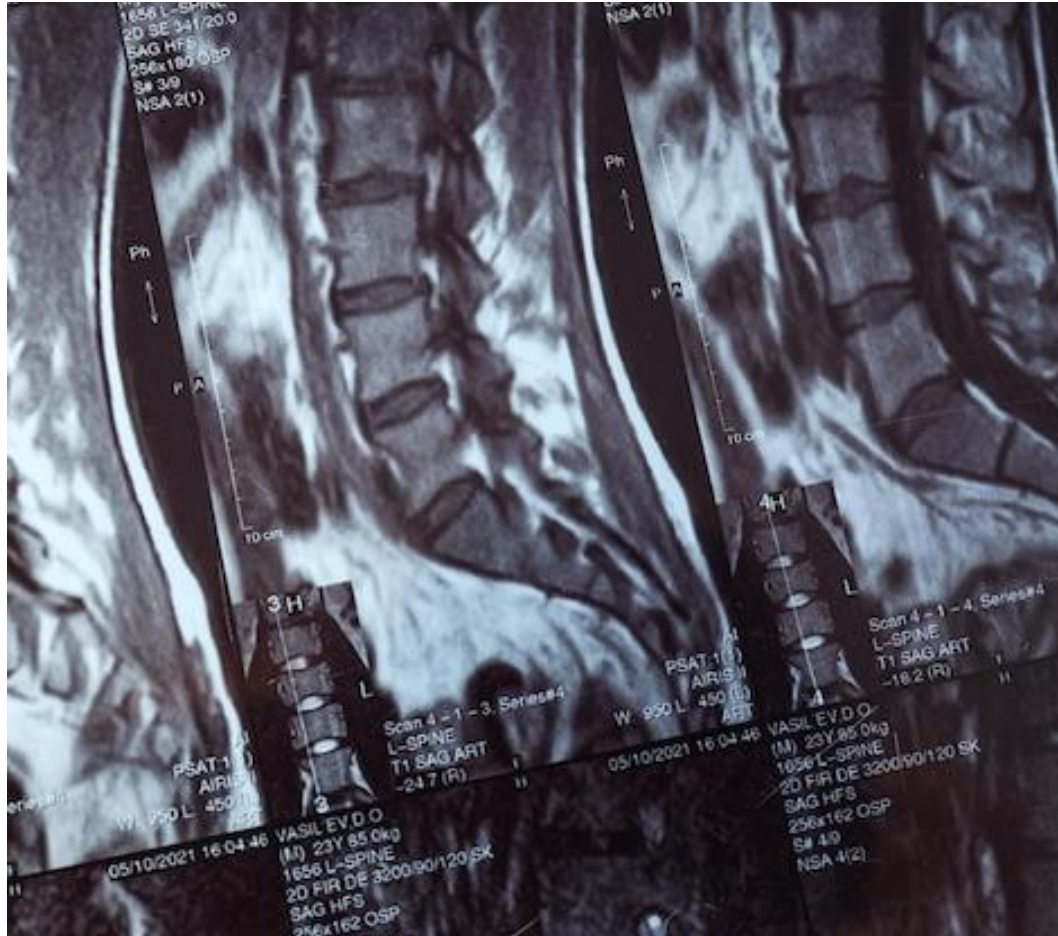
Heel Toe Walk Screen

- **Instructions:** Walk 20 feet on their heels follow by walking 20 feet on their toes twice per day for ten days.
- **Notes:** How does the patient feel, particularly in lower back, legs, and bladder.
- **Logs:** Date, time, low back symptoms, leg symptoms, bladder symptoms.

Differential Diagnosis

- Motor and sensory deficits will not follow a normal myotomal/dermatomal pattern.
- Coughing and sneezing will not aggravate the pain.
- Lying supine will not make the pain better.
- Pain is intermittent.

Imaging Pearls



Lumbar MRI without contrast in supine

- Rule out other causes for pain.
- Determine conus level using axial images. Low lying conus is L2-3.
- Cauda equina may obscure conus tip on sagittal images, stimulating elongated conus.
- Filum thickness is measured at L5/S1.
- Recognize that scoliosis restricts normal cord mobility.

Urodynamic Testing



Conditions that Mimic Tethered Cord

- Spinal cord tumors: There may be pain, motor, and sensory deficits (dependent on location of the tumor) and in rare cases, bladder control could be affected.
- Peripheral Neuropathy: Damage to the peripheral nerves can lead to pain, altered sensation and weakness.
- Myelopathies: Spinal conditions including spinal cord compression, spondylosis, and damage due to inflammation or lack of blood supply.


Non-surgical Treatment Options

- Limit forward flexion
- Lumbar support while seated
- Foam roller under knees when long sitting
- Steroid burst when flared
- Lidocaine patches
- Cox 2 inhibitors
- Anticonvulsants
- Tricyclic antidepressants.
- Physical and Occupational therapy

Case Outcome

Symptom Update for 12 month follow up			Note: Columns in blue are written prior to first appt, August 2020					
Symptom	10/7/21: 12 month follow up: How much has symptom improved since surgery 10/6/20?	1/21/21: 3 month follow up: How much has symptom improved since surgery 10/6/20?	Duration/Since	Frequency	Severity (0-10)	Anything improve symptom?	Anything worsen symptoms?	Have symptoms progressed?
Leg aching pain	gone	80% better	Early 2017	daily (mainly during night)	5-8, primarily at night	not really, but moving my legs relieves it for time I am moving them	standing, taking a shower, and walking	Yes, increased frequency, nightly since May 2020, happening more often in the day since July 27, 2020
Leg weakness	gone	gone	Nov. 2016	constant	7-10	worst symptom I have, I can barely walk	menstruation	Yes
Leg burning pain/sensation	gone	80% better	Late 2017	3-4 x weekly at night	8	nothing can get rid of it	using my legs	Yes, increased frequency and now occurring when have barely used legs
Leg tingling	gone	40% better	Nov. 2016	daily (mainly during night)	6	nothing	not sure	Yes, worse in last few months; did not begin as daily and multiple times per day
Leg heaviness	gone	gone	Nov. 2016	constant	7-9	thigh high compression stockings (20-30) help a bit, but do not relieve it	no	Not sure
low back pain	gone	gone	2001		1-10	lying in bed all day, does not respond to NSAIDS	sitting upright, bending, lifting, carrying 4 lbs., sex, menstruation	No, usually cope with inactivity
extreme leg weakness and worse back pain during periods	80% better	60% better	menarchy	constant	6-10	birth control pill beginning at age 17 improved, but did not eliminate symptoms	not sure	Worse since Nov. 2016
urinary frequency	gone	90% better	2005	15-20x daily	NA	no	worse at night when trying to sleep and first hours awake; standing up; riding in car	Yes, worse since October 2019, and lately going 20x/day more often

Long-term outcome following surgical treatment of posttraumatic tethered cord syndrome: a retrospective population-based cohort study

[Vasilios Stenimahitis](#), [Alexander Fletcher-Sandersjö](#), [Charles Tatter](#), [Adrian Elmi-Terander](#)  & [Erik Edström](#)

[Spinal Cord](#) **60**, 516–521 (2022) | [Cite this article](#)

References

1. Amiri, A. R., Kaneshalingam, K., Srinivasan, V., & Price, R. F. (2013). Adult tethered cord syndrome resembling plantar fasciitis and peripheral neuropathy. *BMJ case reports*, 2013, bcr2013201437. <https://doi.org/10.1136/bcr-2013-201437>
2. Fenton, Douglas. "Tethered Cord Syndrome." *Tethered Cord Syndrome - an Overview | ScienceDirect Topics*, 2011, www.sciencedirect.com/topics/medicine-and-dentistry/tethered-cord-syndrome.
3. Klinge, Petra. "The Concept of Human Tethered Cord Syndrome." *YouTube*, 2022 ASAP Chiari & Syringomyelia Conference, 24 Oct. 2022, www.youtube.com/watch?v=eK0iwKa4IPo.
4. Sinn, Clarice. "Tethered Cord Syndrome." *PM&R KnowledgeNow*, 12 May 2021, now.aapmr.org/tethered-cord-syndrome-2/.
5. Stenimahitis, V., Fletcher-Sandersjö, A., Tatter, C. *et al.* Long-term outcome following surgical treatment of posttraumatic tethered cord syndrome: a retrospective population-based cohort study. *Spinal Cord* **60**, 516–521 (2022). <https://doi.org/10.1038/s41393-022-00752-7>
6. "Tethered Cord Syndrome." *Physiopedia*, www.physio-pedia.com/Tethered_cord_syndrome. Accessed 16 Jan. 2024.