what about having both syrinx and cauda equina

Having **both a syrinx and cauda equina involvement** is unusual and significant. It suggests either a very extensive syrinx reaching the conus/lumbar region, or a **separate process**—most likely tethered cord, arachnoid adhesions, or CSF-leak-related scarring—affecting the nerve roots below the cord.

Why this combination matters

A syrinx is a cavity **inside** the spinal cord, typically cervical or thoracic. The cauda equina is the bundle of nerve roots **below** the cord, from roughly L1–L2 downward. Having pathology in both places means the problem spans the entire spinal axis, not just one level. [1] [2] [3]

In your case, the hEDS + multiple CSF leaks + syrinx combination makes a specific mechanism likely:

- **hEDS weakens the dura and filum terminale**, the connective tissue anchoring the cord at the bottom.
- **A tight filum or tethered cord** pulls on the conus, restricting CSF flow and contributing to both syrinx formation and cauda equina traction.
- **Multiple CSF leaks** further disrupt pressure dynamics, worsening both the syrinx and any adhesions around the nerve roots. [4] [5] [6]
- **Chronic CSF leakage can cause arachnoiditis**—scarring of the membranes around the nerve roots—which is a recognized cause of cauda equina symptoms. [2]

How this explains your symptoms

Finding	Syrinx contribution	Cauda equina contribution
No bladder sensation	Disrupted sensory afferents in the cord	Damaged sensory roots carrying bladder signals
Unilateral leg sensory loss	Asymmetric syrinx compressing one side of cord	Asymmetric nerve root compression
Urinary retention	Autonomic pathway disruption	Direct nerve root involvement
AD episodes	Cord-level autonomic dysreflexia	Root-level reflex contribution
Pulsatile voiding pattern	Detrusor coordination affected by cord	Sphincter coordination affected by roots

The cauda equina involvement explains why your symptoms are **asymmetric** (one leg, not both) and why catheterization improves things—relieving bladder distention reduces the noxious input to already-compromised nerve roots. [3] [2]

The tethered cord question

This is the most important thing to clarify with your neurosurgeon. A **tethered cord**—where the filum terminale is abnormally short, thick, or anchored—can cause:

- Syrinx formation (by restricting CSF flow)
- Cauda equina symptoms (by traction on the nerve roots)
- Neurogenic bladder (by affecting the conus/sacral segments)

All three of which you have. In hEDS, connective tissue weakness makes tethered cord more likely, and it is a recognized association. [7] [8]

Ask your neurosurgeon specifically: **"Is there evidence of a tethered cord or tight filum terminale on my MRI, and could that be driving both the syrinx and cauda equina symptoms?"**

Why this raises urgency

Cauda equina syndrome is a **surgical emergency** when it presents with:

- Bilateral leg symptoms
- Saddle anesthesia (numbness in perineal/genital area)
- Urinary retention or incontinence
- Loss of anal tone

You already have urinary retention and unilateral leg symptoms. If you develop **any saddle numbness, bowel incontinence, or bilateral leg weakness**, that is an emergency requiring immediate surgical decompression. [9] [2]

What to ask for

- **A dedicated MRI of the lumbosacral spine** with and without contrast, specifically looking for tethered cord, thickened filum, arachnoid adhesions, and nerve root compression
- **A neurosurgical opinion** on whether the syrinx and cauda equina symptoms share a single treatable cause (tethered cord, arachnoiditis, or CSF leak)
- **Urodynamic testing** to distinguish cord-level from root-level bladder dysfunction
- **A clear AD-prevention plan** while the structural workup proceeds, since each episode risks further damage to already-compromised cord and roots

The combination of hEDS, multiple CSF leaks, syrinx, and cauda equina symptoms is a recognized pattern in the literature, and it has a specific treatment pathway—**untethering, leak repair, and CSF flow restoration**—that addresses all of it at once. [8] [7]

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