perplexity

Questions for the leak specialist

Ask these directly, in this order:

1. "You ordered a brain-only follow-up MRI five months after my last scan, with no treatment in between. What specific question is this answering—progression of brain sag, or something else?"
2. "I have at least three CSF leaks, a syrinx, and cauda equina involvement. Why is the spine not being imaged when the leaks and syrinx are spinal?"
3. "Is there evidence of tethered cord or a tight filum terminale on any of my prior MRIs, and could that be driving both the syrinx and cauda equina symptoms?"
4. "Have my prior images from [hospital A / B / C] been formally requested through the provincial imaging network, or are you relying only on the reports?"
5. "What is your plan for the leaks—EBP, targeted patch, or surgical repair—and at what point does that happen?"
6. "My bladder distention triggers autonomic symptoms that resolve with catheterization. Is that AD, and how does that change the urgency of treating the leak?"
7. "If the brain MRI shows improvement but my leg sensation and bladder function do not, what is the next step?"

How hEDS complicates CSF leaks and syrinx

hEDS weakens collagen throughout the body, including the dura mater that holds CSF around the spinal cord. That makes spontaneous dural tears—CSF leaks—far more likely, and multiple leaks are well documented in hEDS patients. [1] [2] [3] [4]

The chain is: weak dura → CSF escapes → intracranial pressure drops → brain sags and cerebellar tonsils descend → CSF flow through the spinal canal is obstructed → syrinx forms. [5] [6] [7]

hEDS also weakens the filum terminale, the connective tissue anchoring the cord at the bottom. A tight or tethered filum pulls on the conus, restricting CSF flow further and contributing to both syrinx formation and cauda equina traction. [8] [9]

This means your case is not a simple "one leak, one patch" situation. Multiple leaks plus a syrinx plus cauda equina involvement in hEDS requires a specialist who understands the connective tissue component, not just a generic SIH protocol. [4] [10]

Can a bladder issue cause AD

Yes, and in your case it almost certainly is. Bladder distention is the **single most common trigger** of autonomic dysreflexia, accounting for the majority of episodes.[11] [12] [13]

The mechanism: a full bladder sends noxious signals up the spinal cord. In someone with impaired autonomic regulation—whether from syrinx, hEDS-related dysautonomia, or both—those signals trigger an unopposed sympathetic surge: vasoconstriction, hypertension, sweating, nasal congestion, and airway changes.[13] [14]

Your pattern—symptoms build as the bladder fills, resolve within an hour of catheterization—is textbook AD triggered by bladder distention. The fact that you have no sensation does not mean AD is not happening; it means you cannot feel the warning signs and are only detecting the downstream effects.[14] [11]

What a brain-only MRI shows for SIH

A brain MRI with contrast can show the classic SIH signs, remembered by the mnemonic **SEEPS**:

- **S** – Sagging brain (downward displacement of brainstem, tonsils, third ventricle floor)
- **E** – Enhancement of the pachymeninges (dural lining)
- **E** – Enlargement of veins and dural sinuses
- **P** – Pituitary enlargement/hyperemia
- **S** – Subdural hygromas or hematomas[15] [16] [17]

These signs confirm whether intracranial hypotension is present and whether it is worsening, stable, or improving between scans.[16] [18] [19]

What a brain-only MRI **cannot** show:

- The location or number of spinal CSF leaks
- The syrinx
- Cauda equina compression or tethered cord
- Any change in your leg sensation or bladder function

That is why a brain-only follow-up is insufficient for your case. It answers "is the intracranial hypotension progressing?" but not "is the syrinx growing, are the leaks changing, or is the cauda equina being further compressed?"[18] [20]

How to get doctors to look at DICOM files

The most reliable route is to **stop trying to hand them files and make the hospital request them instead**:

- Ask the leak specialist's office to submit a formal **image-sharing request** through the provincial PACS network (in Ontario, this is typically through the Diagnostic Imaging

network or Ontario Health's image-sharing system). This puts the burden on the hospitals' IT departments, not on you.

- If the specialist's hospital cannot access the other province's images directly, ask them to **request the prior reports in writing** and note the prior findings in their comparison. Reports always transfer; images are the barrier.
- If you must provide files yourself, bring them on a **standard CD/DVD in DICOM format** to the appointment and ask the **radiologist directly**, not the referring clinician. Radiologists are the ones who read images; the referring doctor may simply not have a workflow for it.
- Ask the imaging department: "Do you have a policy for importing outside DICOM media, and if so, what is the process?" Some departments will import them if asked through the right channel, even if the front-desk staff says no.

The key is to route the request through the **imaging department's formal process**, not through individual clinicians who may not have the authority or workflow to accept outside media. [21]

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