ACMCRN
ARACHNOIDITIS & CHRONIC MENINGITIS COLLABORATIVE RESEARCH NETWORK
EDUCATION • RESEARCH • ADVOCACY • SUPPORT

Medical Alert and Advocacy Sheet
For patients and their healthcare providers
ACMCRN.org

MEDICAL ALERT: Adhesive Arachnoiditis

Please read before any spinal procedure, injection, anesthesia, or imaging.

☐ **Confirmed diagnosis.** Confirmed by _____ on _____

☐ **Suspected, not yet diagnosed.**
This patient has symptoms consistent with Adhesive Arachnoiditis and is requesting evaluation. **Please see the back of this sheet.**

Patient details

Name		
Date of birth		
Treating physician and phone		
Emergency contact and phone		
Current medications		☐ See attached sheet
Allergies		☐ See attached sheet

If anything doesn't fit, tick "See attached sheet" and staple a page with the full details behind this one.

Procedures to avoid, or discuss with my treating physician first

Each of these enters the spinal canal and can worsen the inflammation and scarring of Adhesive Arachnoiditis.

- Epidural steroid injections and nerve blocks into the spinal canal
- Lumbar puncture (spinal tap) and myelogram
- Spinal or epidural anesthesia. Please discuss whether general anesthesia or another approach is possible.
- Any intrathecal injection
- Spinal surgery, unless discussed with my treating physician

What the FDA and the manufacturer say

- In April 2014, the FDA required a warning on all injectable corticosteroid labels about rare but serious neurological events after epidural injection, including paralysis, stroke, and death.
- Corticosteroids are not FDA-approved for epidural use. The manufacturer's label for Depo-Medrol states this.
- As of April 2014, the FDA had received 41 reports of Arachnoiditis linked to epidural steroid injections.

Sources are listed on the back.

Imaging preferences

- A high-resolution MRI without contrast is preferred for diagnosing and monitoring Adhesive Arachnoiditis.
- Contrast only when there is a specific clinical reason, such as a suspected spinal fluid leak, or to exclude the possibility of an (enhancing) spinal tumor at initial diagnosis.

Patient name _____

If Adhesive Arachnoiditis is suspected

Complete this section only if you ticked "Suspected" on the front. If your diagnosis is confirmed, skip to **Care needs**.

Spinal procedures, injuries, or infections, if any **Date**

_____ _____

_____ _____

☐ More: see attached sheet

Symptoms started _____ **Possible cause** _____ ☐ Unknown

Main symptoms

☐ Burning, stabbing, or electric pain
☐ Leg or arm pain
☐ Numbness or tingling
☐ Weakness
☐ Bladder or bowel changes
☐ Headaches
☐ Other: _____

I am requesting

1. A high-resolution lumbar MRI without contrast.
2. That the radiologist specifically look for clumped nerve roots, nerve roots displaced to the edges of the spinal sac ("empty sac" sign), and thickened membranes.
3. That myelograms and lumbar punctures not be used to diagnose me, since they enter the spinal canal.
4. That elective spinal procedures, including injections, be postponed until Adhesive Arachnoiditis is ruled out.

Symptoms that begin soon after a spinal procedure, injury, or infection are worth evaluating promptly.

Care needs during visits and hospital stays

Positions I tolerate _____

Positions to avoid / sitting or lying limits _____

Rescue medication plan _____

Mobility aids I use _____

Transfers, long waits, and procedures can trigger severe pain flares. ☐ Full care plan: see attached

Seek urgent evaluation if I have

- New or worsening weakness in my legs or arms
- Loss of bladder or bowel control
- Numbness that is spreading quickly
- Severe pain that is unusual for me or doesn't respond to my rescue medication

More for providers: ACMCRN.org/about-arachnoiditis This sheet is for information and advocacy. It does not replace medical advice from the patient's physician.

Sources: FDA Drug Safety Communication, Apr 23, 2014 (fda.gov/Drugs/DrugSafety/ucm394280.htm). Depo-Medrol prescribing information, Warnings section (accessdata.fda.gov). FDA advisory committee report of 41 Arachnoiditis cases in FAERS as of Apr 2014.

Version: v1.0, November 2026