





PAIN PUMPS

DO'S, DON'TS AND THINGS THEY WON'T TELL YOU



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Critical Warnings and Screening Before Pain Pump Implantation

It is my strong opinion that getting a pain pump should be the **absolute last resort** in treatment for chronic pain. This is a targeted therapy delivered to the spinal cord; it does not guarantee relief for full body pain.

Warning for Adhesive Arachnoiditis (AA) Sufferers

CRITICAL WARNING FOR AA PATIENTS: The physical act of having the pain pump implanted, and specifically the insertion of the catheter inside the spinal column, carries an **increased risk of your Arachnoiditis progressing** [Ref 5]. You must choose a surgeon and a pain specialist highly familiar with treating Adhesive Arachnoiditis.

Screening for Undiagnosed Arachnoiditis

It is believed that approximately **10% of patients with a diagnosis of Failed Back Surgery Syndrome (FBSS) actually have Arachnoiditis**. If you are in this category, please get screened for AA, especially if you suffer from:

- Burning feet or legs.
- Unusual skin symptoms such as feeling water running down your legs, or insects crawling on your legs (paresthesia).

If you have these symptoms, **you must research Arachnoiditis first**. Managing neuroinflammation post-surgically is vital.



What is an Intrathecal Pain Pump?

A pain pump system has two major parts: the **pump reservoir** (implanted under the skin) that holds medication, and the **catheter** (medication tubing) that delivers the drug directly to the spinal cord nerves.

A pain pump does not always cover full body pain. It's a targeted therapy that's delivered directly to the epidural space in your spinal cord. It can only help with painful conditions that arise from traveling on the nerves from or to the spinal cord. Be sure and discuss what areas the pain pump will cover for pain control before getting the pain pump. The pump usually only covers the targeted area of the catheter, and 3-4 levels up or down from the catheter placement. Dosage can affect coverage too. If the dosage is extremely low, you will have less therapeutic efficacy and less area of coverage.

Device and Procedure Basics

- **Programming:** The pump can be fixed-rate or variable-rate, often with patient-controlled analgesia (PCA) bolus options.
- **Implantation Site:** The pump reservoir is implanted in the **abdomen** or, the **lower back/upper buttock** (which is less affected by weight changes), but can be uncomfortable.
- **Battery Lifespan:** The typical lifespan for a modern pump battery is **5 to 7 years**, requiring a surgical replacement [Ref 4].
- **Refills:** Refilling is an outpatient procedure using a needle inserted through the skin. Refill frequency ranges from monthly to every 6 months. I don't particularly consider it painful, but if it's done by an inexperienced person, and they have to do multiple attempts to find the access port, that can get painful. Depending on the facility, you can request a numbing agent

Benefits of Pain Pumps

Intrathecal pumps can offer significant relief [Ref 1]:

- Reduced or eliminated use of high-dose oral pain medication.
- Improved ability to function and participate in everyday activities.
- Reduced side effects compared with systemic (oral) medication.

Key Complications and Risks of Pain Pumps

- **Catheter Complications:** This is the most common mechanical issue. Risks include **kinking, breakage, dislodgement, or leakage**, which can lead to abrupt under-dosing and withdrawal.
 - **Granulomas:** Inflammatory tissue masses at the catheter tip, often associated with high medication concentration.
 - Anchor breaking and **pump flipping** (requires surgical correction).
 - Drug overdose/underdose from incorrect settings, mechanical failure, or drug degradation.
 - **Hormone changes** for both men and women common with long term opioid use.
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Medication Options and Dosing Challenges

FDA Approved Medications:

- **Morphine Sulfate:** Most common opioid.
- **Ziconotide/Prialt:** Used for patients intolerant of morphine.
- **Lioresal (Baclofen):** Primarily FDA-approved for severe muscle spasms (spasticity) but can be used in pain cocktails.

Off-Label Medications:

Physicians may use combinations (**cocktails**) or single off-label drugs, though **not all pump physicians use mixtures**.

- Fentanyl
- Hydromorphone
- Clonidine
- Ketamine
- **Bupivacaine** (Local Anesthetic).

Critical Dosing and Titration Insights

- **Lack of Standardization:** Because there are **no universal standards**, prescribed dosages and maximum limits vary widely among physicians.
 - **Prialt (Ziconotide) Warning:** This drug **must be started at a very low dose and titrated slowly** to mitigate severe side effects, which can include confusion, memory loss, and psychiatric issues like hearing voices.
 - **Bupivacaine Caution:** Local anesthetics like Bupivacaine may address **nerve pain** (neuropathic pain), but **must be started at a very low dose** and titrated slowly, as high levels can be **toxic to nerves** and cause permanent damage
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Patient Dos, Don'ts, and Unspoken Truths

Do's

(Actionable Safety & Management)

- **VERIFY DOSAGE CONVERSIONS:** Always request and verify the dosage calculations when your pump medication type is being changed. A miscalculation can throw you into acute withdrawal.
- **Plan Refills with a Buffer:** Schedule refills **at least two weeks** before the due date. This buffer is essential for compounding pharmacy time, unexpected delays (illness, car trouble), and long travel times required for appointments.
- **Report Complications to the FDA:** Patients must report any serious problems or device malfunctions directly to the FDA MedWatch portal (Link: <https://www.fda.gov/safety/medwatch-fda-safety-information-and-adverse-event-reporting-program/reporting-serious-problems-fda>).
- **Plan for Long-Term Care:** Due to the decreasing number of specialists, **always take into account future stability, including the possibility of moving**. Research potential doctors in new locations *before* relocating.
- **Carry Narcan:** Always carry Narcan (Naloxone) for potential opioid overdoses.
- **Telemetry Detail:** "Do get your telemetry print out every single time your pump is scanned, regardless of whether or not it's a pump fill. A pain pump telemetry is a form that's given to you at the time of pain pump service that shows important information about your pain pump status such as; dosage before and after the pump refill; bolus

amount if any; pump run out date; battery run out date; what's in your pump; and the dosage.



(Critical Warnings)

LIFE-THREATENING HEAT WARNING: DON'T expose yourself to temperatures above **102.2° F (39° C)**, including hot tubs, saunas, and high fever. High temperatures can dangerously increase the pump's flow rate, leading to a severe overdose [Ref 2].

- **Catheter and Anchor Failure:** Includes kinking, leakage, or fracture of the catheter. **High-impact activities can cause the anchors to break, leading to pump flipping, or cause the catheter to dislodge, resulting in medication leaking into tissues or the spinal canal.**
- **DON'T** engage in scuba diving or fly in **unpressurized cabins**.

Unspoken Truths (Insider Patient Knowledge)

- **Pre-Surgical Withdrawal Challenge:** Some doctors require you to completely stop all oral pain medications before surgery. Prepare for the severe pain and withdrawal this can cause, and advocate for comfort measures.
- **Lack of Breakthrough Meds:** Be aware that some pump doctors will not provide breakthrough pain medication while you wait for the pump to be titrated or for post-operative pain management.
- **Medication Efficacy Loss:** Independent studies have shown **substantial decreases in the efficacy of certain medications** over long refill cycles. If your pain relief suddenly drops near the refill due date, the drug may be degrading inside the pump.
- **Refill Overdose Risk ("Pocket Fill"):** During refills, there is a risk of the needle missing the port, causing the drug to leak into tissue and leading to an acute overdose.
- **Refill Travel Burden:** Many pump patients must travel long distances for refills, making scheduling a major life commitment.
- **The DEA Effect:** Opioid availability is being cut every year by the DEA. Discuss how potential future cuts will affect your prescribed intrathecal medication.

- **Pump Battery:** The **pump's battery replacement date is a hard deadline**. Start the process for surgical replacement (insurance approval, scheduling) at least six months ahead of time.
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Conclusion

This guide, informed by the collective experience of the chronic pain community and the **ACMCRN** organization, is a powerful tool for empowerment. We encourage patients to utilize this comprehensive knowledge to engage proactively with their treatment team and make informed, cautious decisions regarding intrathecal therapy.

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Disclaimer: This information does not substitute for medical advice. Please consult your provider and device manuals.

References and Further Reading

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