

Do's, Don'ts, and Things They Won't Tell You About an Intrathecal Pain Pump

Introduction

My name is Eve Blackburn, I'm an adhesive arachnoiditis sufferer and I've been a pain pump patient since 2000. I felt that there was a need for a paper such as this one to give chronic pain patients information that they can use when making the important decision on whether or not to get an intrathecal pain pump, and information for patients who already have a pain pump.

This guide is not a substitute for the manufacturers pain pump manuals that are available for your particular make and model. Be sure to consult your manufacturer's documentation.

For my fellow adhesive arachnoiditis sufferers, you'll need to keep in mind that the catheter is inserted into the epidural space and your scar tissue might obstruct them from successfully placing the catheter. For myself, my surgeon placed the catheter at my lower thoracic level upside down to avoid the lumbar area where my adhesive arachnoiditis is and the scar tissue. I'll be looking into this more, but I suggest that you consider this option if you decide to get a pain pump.

There's also an increased risk of your arachnoiditis progressing. I highly recommend that you pick a surgeon familiar with arachnoiditis. I think this warning is important for patients who've been diagnosed with failed back syndrome (FBS) and suffer from burning feet/legs and unusual symptoms such as water running down your legs, or insects crawling on your legs. These are common signs of arachnoiditis or adhesive arachnoiditis. If you have these symptoms, and are considering getting a pain pump, I highly recommend that you do some research on arachnoiditis first because managing neuroinflammation post-surgically is very important with an inflammatory condition of the spine such as arachnoiditis. I will put some useful links at the end of this paper.

First off, let me start by stating that getting a pain pump should be the absolute last resort in getting treatment for chronic pain. 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.

IMPORTANT: It's been about a year since I wrote the article and I wanted to add some important information that I've read about in the pain pump Facebook support groups that I consider important before you start reading this article.

My first comment is that there's very little consistency in what medications physicians who manage pain pumps put in your pump and at what dose. I compare this to the wild west. There really aren't any regulations on this. Even though the FDA put out an [alert](#) on using medications in pain pumps that aren't approved, pain pump doctors continue to use non-approved medications, even a combination of them. I'm not necessarily knocking this, but it's very important that you find out what they will use in your pump and make your decision. I personally have a combination in mine, but it's a choice that I've decided to make for my particular situation.

The other thing you need to ask about is what medications, if any, does your insurance company pay for. You'll need to call your insurance company to find this out. Not all insurance companies cover the medications, so you need to have a plan in case your insurance company doesn't pay for the medications. There is some help out there for this [AIS Healthcare](#), who compounds and delivers the medications, has financial assistance with low or no copays depending on your income level. They also have Home Connect, a service that will come out to your home and fill the pump, along with other services.

What is a Pain Pump?

A pain pump consists of two major parts:

- 1) the pump reservoir that holds pain medication, and
- 2) the medication tubing (catheter) that carries pain medication to the spinal cord nerves.

The pump can be programmed to be a fixed-rate, constant flow device or a variable rate pump with the option of boluses via patient controlled analgesia programming using a wireless radio frequency transmitter given to the patient

The pump is filled in an outpatient setting using a needle through the skin and into an access port in the top of the pump's reservoir. How painful that is depends on the person getting the injection and the medical professional doing the procedure. 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.

How often the pump needs to be refilled depends on the reservoir size and the dosage. You can expect refills to occur anywhere from monthly to every 6 months.

The pump reservoir is implanted either in your abdomen- or in your lower back/upper buttock. The advantage of having the pump implanted in the back instead of the abdomen is weight changes don't affect the pump from shifting, particularly for women.

Intrathecal pumps can alleviate both pain and muscle spasms associated with:

- Failed back surgery

- Cancer
- Cerebral palsy
- Multiple sclerosis
- Chronic pancreatitis
- Arachnoiditis
- Abdominal Pain
- Radiculopathy

Benefits and Risks

- Reduced or eliminated use of pain medication. This depends on where your pain is located.
- Improved ability to function and participate in everyday activities.
- Reduced side effects compared with oral medication

Complications may include:

- Anchor breaking and pump flipping
- Granulomas (inflammatory mass at catheter tip usually associated with high concentration of medication in your pump)
- Infection (usually surgical related)
- Spinal fluid leaks (usually surgical related)
- Parts of the implantable pump system, including the catheter or pump could leak, tear, kink, or become disconnected causing drug overdose/underdose
- Battery problem or component failure
- Drug underdose/overdose from pump settings incorrect, overheating, flying, diving, short shelf life of pain medication
- Drug allergies
- Hormone changes for men and women

Pain Pump Trial

This is an important step in determining if you are a good candidate for the pain pump. The pain pump trial is generally done in an outpatient setting. You might be given sedation (depending on doctor) to make you comfortable, and then you will be given numbing medication (typically bupivacaine). An epidural needle is then inserted into the intrathecal space using x-ray guidance. Once proper position is confirmed, a small catheter is inserted through the needle and into the intrathecal space. Once that placement is confirmed, they inject concentrated pain medication. You'll then be sent to a recovery room where you'll be monitored to see how well the medication is working. A second dose may be administered during this time. If the trial is a success, you'll be set up with a permanent pain pump implant surgery.

Medication Options.

The medications that are FDA approved for intrathecal pain pumps are:

- Morphine Sulfate. Most common
- Lioresal (baclofen) FDA-approved drug used for treatment of muscle spasms.
- Ziconotide/Prial is commonly used for patients who cannot tolerate/allergic to intrathecal morphine.

Some physicians will only fill the pump with FDA approved medications for pain pumps, but some are willing to add other medications. Here are just a few of them:

- Fentanyl
- Clonidine
- Ketamine
- Bupivacaine
- Hydromorphone

- ❖ Research the side effects of each medication you're considering.
- ❖ Watch out for pain medications such as fentanyl and hydromorphone that have a short Shelf life. Shelf life is the amount of time a medication can be stored without losing its effectiveness. Since the medication is stored in the pump reservoir, this is an important consideration. Short shelf life can cause loss of efficacy and even withdrawal symptoms.
- ❖ If you have the smaller 20mL reservoir you probably won't need to worry about the shelf life.

You might want to read this FDA alert about approved pain medications:

<https://www.fda.gov/news-events/press-announcements/fda-alerts-doctors-patients-about-risk-complications-when-certain-implanted-pumps-are-used-deliver>

Do's and Don'ts of a Pain Pump

Do:

- Do watch out for side effects from the drugs (over- or underdose) which may include respiratory depression, twitching, muscle spasm, urinary retention, constipation, nausea, vomiting, dizziness, anxiety, depression, and edema. *Call 911 if you suspect you're going through this. Have your pain pump card and telemetry handy.
- Check the shelf life of non-FDA approved pain medications such as fentanyl and hydromorphone. A short shelf life can cause loss of efficacy and even withdrawal symptoms as the medication loses its potency.

- Do have a prescription for Narcan with you in the event you suffer an overdose of medication, and additional pain oral pain medications with you in the event you have an underdose situation.. This can happen for a variety of reasons, including pain pump malfunction. Make sure that your family and friends are aware of your situation and what they need to do in the event of an emergency.
- Make your refill appointments at least two weeks early to give a cushion for error. The medication for your pump is compounded by a pharmacy just for you and there can be mistakes or delays in getting it.
- Do give yourself plenty of time to get to your pump refill appointment. This is important, if you're late or miss your pump refill, you can suffer the consequences. It's better to leave early than miss your appointment.
- Do ask what kind of medications they'll be putting in your pump, along with any other important information such as programming options and type and size of pain pump
- Do ask if you're going to be allowed pain medication to control post-surgical pain and breakthrough pain, this is very important. Please keep in mind that your pain pump does not always help with surgical pain and does not always cover conditions that are outside of the targeted area.
- 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.
- It's recommended that you have an MRI scan every 18 months (though I personally check annually) to make sure there are no problems such as a catheter tip granuloma. If you discover a tip granuloma early, it can easily be controlled. If the problem isn't caught early enough, you may require surgery.
- If you're planning on moving out of your area, find a doctor to manage your pain pump before you move. Don't wait until the last minute or after you move.
- If you plan on changing pain pump doctors, make sure that they will keep you on the same medication and dosage.
- Please keep in mind that some pain pump doctors don't always accept patients whose pumps were installed by another physician. Some physicians might not prescribe the type of medication(s) you have in your pump, so it's important to ask this question. There are some that will only put FDA approved medications, there are some who will use non-FDA medications, and there are some who will put multiple medications in a pump. It all depends on the physician.
- 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. What's in your telemetry may vary.
- Occasionally it might be necessary to change the pain medication in your pain pump. Be sure that when the medications are being switched out, that the pain pump doctor

double and triple checks that they made the correct conversion calculation. Errors in dosing rates can have life threatening consequences.

- Newer pain pumps are MRI safe. Following is the MRI procedure for both Medtronic and Flowonix pain pumps. Please check with your pain pump specialist, pain pump representative, or online documentation.
 - With Medtronic SynchroMed II pumps, the pump automatically shuts down during the MRI and restarts after the MRI. Following your MRI, your doctor should check your pump to confirm it is working properly. I've heard that you can also check the pump status with your PTM (handheld device) by giving yourself a bolus, which is a temporary increase in medication. If the pump is stalled, you will not be able to give the bolus. This is not the procedure that Medtronic recommends in their documentation, so I suggest that if you have a Medtronic pump you check with your pump doctor before getting an MRI. For
 - Flowonix pumps must be emptied before the MRI and refilled after the MRI. Always contact your pump doctor before getting an MRI to determine what process you need to take.
- Do get a medical alert bracelet with your pump doctor's information. You should also make sure you have the pain pump implant card that they give you with you at all times, along with your most current telemetry.
- Do let the airline's security know that you have a pain pump implant so they can accommodate you. You can go through x-ray, but you'll set off the metal detector's. You should also let them know whether or not you can stand up for the x-ray. If you cannot, they usually scan you with a handheld metal detector.

Don't:

- Don't spend time in temperatures above 102 degrees Fahrenheit (varies by person). This includes extended trips outdoors, strenuous activities, hot tubs, jacuzzi's, saunas, hot yoga, steam baths, tanning booths, hot pads set on high or directly on the pump-nothing above 102 degrees Fahrenheit. Higher temperatures increase the flow rate and can cause overdose symptoms. Even body temperatures above 102 degree F. If you do find yourself in this situation, beware of symptoms of overdosing including:
 - Lightheadedness and dizziness, progressing to extreme drowsiness and sleepiness
 - Excitability, anxiety.
 - Very slow and shallow breathing (less than 8 to 10 breaths per minute)
 - Unconsciousness or inability to awaken.
- ! Advise your friends and family to call 911 immediately for emergency help if you exhibit any of these symptoms.

- Don't expect hospitals to know anything about pain pumps. Especially if you go to the ER. I always keep my pain pump identification card and a copy of my most recent telemetry. It's best to let your pain specialist know that you're planning on going to the ER.
- Don't sit in direct sunlight for extended periods of time. Most pain pump medications have side effects that will make this activity very uncomfortable, and even dangerous.
- Take frequent breaks to avoid overheating. Bring frozen water bottles/ice packs with you, something to sit on and make sure there's plenty of shade to cool off in. Do not sit in the direct sunshine for extended periods of time.
- No diving below 3 atmospheres, which is about 10' per atmosphere or 30' and you'll need to get your pump refilled 3-4 days max prior to the dive. Pumps can collapse if the reservoir is low. These figures work for hyperbaric chambers too. Please consult with your pain pump manufacturer before doing either of these activities.
- Discontinue any activity such as football, soccer, golf, baseball, wrestling, bowling, etc. Anything that causes you to twist your body or receive an impact to the pump area should be stopped. These activities can cause your catheter to become dislodged which causes your pump medication to leak out into your tissues or spinal canal, and if the anchors that hold your pain pump in place break, it'll cause your pump reservoir to flip. This is not something you want to have happen.
- No extreme bending or twisting.
- No heavy weight lifting
- When flying at higher altitudes, please, consult your user manual for restrictions. Medtronic's SynchroMed II says this about atmospheric pressure:
 - ❖ Atmospheric pressure Patients living or traveling (eg, airline flights, mountain climbing) at altitudes above sea level are exposed to lower atmospheric pressures. Within days of exposure to the lower pressures, the flow rate of the pump can increase and then stabilize at the higher flow rate. In circumstances where a potential increase in flow rate may pose a risk to a patient, reprogramming the infusion prescription offsets this higher flow rate.
 - ❖ In rare instances, exposure to the lower atmospheric pressure can cause the pump to deliver more than 14.5% of the programmed flow rate while the patient is exposed to the lower pressure. Consider changes in drug concentrations or changes to pump programming for patients exposed to lower pressures.

As a final note, I'd like to add that the inconsistency of the types of medications physicians will add to a pain pump, and the dosing of these medications fluctuate so wildly from doctor to doctor that I call it the wild west. There's really no regulations for this. Please make sure that you ask the

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<https://www.facebook.com/groups/1719448041456829/>

References:

- Synchromed II implant Manual

http://www.neuromodulation.ch/sites/default/files/pictures/synchromed_II_implant_manuel.pdf

Useful links

- AIS Healthcare-financial assistance for medications. In-home pump refills:
<https://www.aishealthcarepharmacy.com/our-divisions/targeted-drug-delivery/for-patients/>
- Information on arachnoiditis: <https://arachnoiditishope.com/diagnosis/>
- Medtronic's Website: <https://www.medtronic.com/us-en/index.html>
- Flowonix Website: <https://flowonix.com/healthcare-provider/products/prometra-pump>
- Video of how a pain pump works. This is for a Flowonix, but is a good representation for Medtronics: <https://m.youtube.com/watch?v=jFbGGitBpTc&feature=youtu.be>
- FDA alert for approved intrathecal medications
<https://www.fda.gov/news-events/press-announcements/fda-alerts-doctors-patients-about-risk-complications-when-certain-implanted-pumps-are-used-deliver>