



Information after Baclofen Pump Implant

- Your child’s “pump” is an implanted device that contains baclofen, which is being delivered directly into the intrathecal space (area around the spinal cord). The pump holds either 20cc or 40cc of medicine. When the specialized computer “reads” the pump, it can tell which size, what type/concentration of medicine is in it, and what dose your child is getting. The pump is very safe and very little can disrupt its function.
- Medtronic will mail an emergency card with our number and Medtronic’s number to you shortly after you leave the hospital. Information about your pump is on this card. Always carry the emergency card and plastic guide so the local ER will know whom to contact if needed.

Pump Site:

- For a few days or weeks after surgery, your child may have a small collection of fluid around the top and sides of the pump, or on the back. You may use an ace wrap around the belly to reduce this swelling.
- Call your physician/surgeon if redness or drainage is noted around the incision sites.

Activity:

- Avoid activities that require excessive bending or turning at the waist for about 6 weeks to reduce stress on the incision. After the incisions have healed, regular activities may be resumed.

Wound Care:

- Do not take a tub bath or swim until the incisions have completely healed. You may shower as long as you keep the incisions dry. Cover them with a gauze and plastic wrap
- Wear loose clothing over the pump pocket site to maintain comfort and prevent skin irritation.
- If your child has steristrips, they will fall off on their own or may be removed after 2 weeks.

Medications:

- You may use acetaminophen (Tylenol) or Ibuprofen (Motrin) if desired for pain.
- Never stop oral antispasmodic medication (like baclofen or dantrium) abruptly, as withdrawal of these medications can cause discomfort and increased tone. You will be given a schedule to gradually reduce these medications.

Constipation:

- Constipation may temporarily worsen because of narcotics given for pain relief. Your child should have a bowel movement at least every 2-3 days, and you may need to increase their regular bowel program or add a stool softener. Call if there is no improvement.

Diet:

- Your child may resume his/her usual diet.



Complications-- Call Your Doctor if...

- Fever over 101° F.
- Increased pain, redness, swelling, or drainage from/around the incision.
- Increased weakness, difficulty breathing, drowsiness (excessive sleepiness), lightheadedness, slurred speech, double or blurred vision, or itching.
- Increased severe spasticity that comes on suddenly is accompanied by itching or withdrawal like symptoms.

Therapy/ Equipment

- Be aware that your child's sitting, mobility, gait and *your* ability to do transfers may be different, as their "center of gravity" and stability may change after implant. Learning new balance and movement patterns will take time.
- You may begin PT, OT and Speech to strengthen and stretch muscles groups within 2 weeks of surgery. Avoid full forward bending and twisting for about 6 weeks, as mentioned above.
- Water therapy, belly crawling etc. are fine once the surgical incisions are fully healed.
- Reassessment of orthoses/braces, wheelchairs, and assistive devices may be needed.
- Adjusting the baclofen dose is an ongoing process and therapy goals will be adjusted as the medication dose is changed – feedback from everyone is important!

Other Medical Interventions:

- Avoid radiation therapy, deep ultrasound or lithotripsy directly over the pump.
- X-rays and CT scan are compatible with pumps.
- Magnetic resonance imaging (MRI) is compatible with pumps, but the pump may "beep" while in the machine. This will stop once you are out of the magnetic area. The pump will not deliver medicine while you are in the magnet, and does not "make up" the difference once you are out. Talk to your pump physician if you have questions about having an MRI.

Electrical Devices:

- The Syncromed pump has built-in features to protect it from interference from devices such as telephones, microwave ovens, televisions, small and large appliances, power and gardening tools. You can go through airport security safely.

Travel/Recreation:

- Avoid activities that involve extreme changes of altitude or pressure such as scuba diving, unless approved by your doctor. This may increase or decrease the pressure in the pump and change flow rates.
- Show your pump ID card to airport security staff to aid, help, or ease security clearance. Your pump may set off the metal detector.
- Contact your doctor about travel plans if a pump refill might be needed during that time.



If your pump is beeping...

The pump beeps for several different reasons including:

- *Low on medicine* (beeps single beep once an hour) – You may have only have a day or two worth of medicine left before withdrawal will occur. An appointment needs to be made to fill it! We make all appointment PRIOR to this date.
- *Low battery* – occurs 6 months prior to the battery needing replacement. We will shut off the sound and schedule replacement surgery. Batteries typically last 7 years and your programming slip will tell you how many months are left (“ERI” on the slip)
- *Empty* – no medicine (beeps two tone beep every 10 minutes) – EMERGENCY, withdrawal will begin within several hours if medication is not refilled
- We hope you NEVER hear the pump beep, because it should never be low or out of medicine if your appointments are kept. If the pump beeps a single tone every hour – it needs refilling ASAP. It must not be ignored.

If your child’s spasticity is worse....

- Typically, spasticity gets worse if a person is sick, or has an ear, bladder, respiratory or other infection. Fatigue, cold weather, changes in seizure or other medication, or stress may also make muscle tightness appear worse. It is important to see your primary care physician to rule out any treatable causes of increased spasticity because the majority of the time, the reason for increased tone is **NOT** the pump. You may not notice your child’s tone return to baseline until the infection has cleared up completely.
- Sometimes after a person has been on the same dose of baclofen for a long time or is going through a growth spurt, an increased dose of baclofen will be needed to reduce increased spasticity. This can be done easily in the office either at the time of, or in between refills.
- If the pump or catheter has malfunctioned (disconnected, moved, or broken) you would typically see a fairly sudden and severe increase in tone because baclofen is no longer being delivered. There may be itching, significant increase in spasticity, and overall discomfort. If your child is experiencing withdrawal symptoms, they need to begin taking oral baclofen immediately. You should begin by giving your child 20 -30 mg and then calling us directly. We may increase the dose and frequency, as comfort is our objective, and have you see us or go to the ER immediately. A child will typically require more baclofen that they were taking before the pump was put in.
- If we suspect a problem with the pump and catheter system, we have the ER check an x-ray to start. If nothing is obvious, we may need to inject dye into the catheter or pump to help see it better. This is done in essentially the same way that the pump is refilled-a small needle is inserted into a small port on the pump. If the pump or catheter has a problem, surgery will likely be required to repair it.



If your child is getting too loose...

- It is possible that heat, fatigue, seizures, or changes in other medications may cause a person to appear “looser” than normal. It is also possible that the child has a shunt or central nervous system infection, which needs to be evaluated. Symptoms such as fever, rash, etc. are important to note. If a person seems to be overly relaxed, sedated, or hard to arouse, it is possible that they are receiving too much medication and the dose needs to be adjusted.
- In these circumstances, please call your “pump physician” to help you determine what to do. If your child for any reason is difficulty to arouse or is breathing very slowly, take them to the emergency room or pump physician for immediate evaluation. Sitting the child up will help the baclofen stay in the area of the spinal canal that effects the lower body more that the upper body.
- Typically, after a dose adjustment it will take about 2-6 hours to see a change. The pump can be shut off, but because withdrawal can be uncomfortable, we typically turn down versus turn off the medication.

Follow-up Appointments

- You will receive an appointment upon discharge from the hospital. This appointment will usually occur within 2 weeks of discharge. We will typically see you weekly or biweekly in the first few months, in order to get the baclofen dose adjusted to the best level.
- **At each clinic visit, you will leave with a follow-up appointment timed before your next pump refill is needed. *It is our policy that this MUST be made at the time you leave. This prevents missing a pump refill date.***
- If you need to reschedule it – you *must* call the clinic and tell them it is regarding a pump refill.
- Your child’s spasticity will be evaluated, the pump will be refilled, and the dose adjusted with input from you, your family and therapist. Please bring any input with you to the appointment.
- Follow-up appointment frequency will depend on your child’s functional needs and on the need for refills (typically every 1 – 6 months).
- Please call us with ay questions and if anything changes regarding your pump care!

Pediatric Rehabilitation Medicine Associates

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