



Baclofen Pump

What is a Baclofen pump?

- A Baclofen pump is a little machine which is placed under the skin of the abdomen (belly). It is used to deliver Intrathecal Baclofen, a medication that tells the muscles to relax and can help with spasticity (often due to cerebral palsy or a brain injury). Spasticity is a problem where muscles continually receive messages from the central nervous system to tighten and contract.
- The pump is attached to a catheter (tube) which helps direct the medicine right into a specific area of the spinal cord (called the intrathecal space).

How does it work?

- A neurosurgeon implants the pump (about the size of a computer mouse) into your child's abdomen on one side near the hip bone.
- One end of a catheter is connected to the pump and the other end is inserted into the space surrounding your child's spinal cord.
- A programmer (a very small computer) is used to tell the pump how much medicine to give. The programmer uses telemetry (similar to radio waves) to tell the pump what to do.

What are the possible complications?

- Risk of a bad reaction to anesthesia
- Risk of bleeding
- Risk of infection of pump, catheter, or wound (from surgery)
- Changes in bladder control (most often this is a temporary complication)
- Changes in sexual and bowel function
- Overdose (too much) of baclofen
- Underdose (not enough) of baclofen
- Catheter kink (bent tubing) preventing the flow of baclofen
- Catheter break causing a leak of baclofen

- Catheter disconnection from pump preventing baclofen from reaching spinal cord
- Implant/pump failure or malfunction (not working properly)

Side Effects

Side effects of baclofen include:

- Constipation
- Nausea
- Blurred vision
- Your child can also have side effects if he/she is receiving too much or not enough baclofen.

Too Much Baclofen: Children can get too much baclofen when a catheter is kinked and then becomes unkinked. This can be caused by human error when programming the pump or because your child is sensitive to an increase in their dose of baclofen. It is important to know the signs and symptoms of too much baclofen.

Signs that your child might be getting too much baclofen:

- Looser muscles than usual
- Slow breathing
- Drowsiness
- You can't wake them.

Not Enough Baclofen: After a short time your child's body will become dependent on the baclofen. If for any reason they suddenly stop getting baclofen it can make them very sick. This can happen because of a problem with the pump, a crack or break in the tubing, or movement of the tubing.

Signs that your child may not be receiving enough baclofen:

- Tighter muscles than usual
- High temperature
- Itchy skin
- Irritability (grumpiness)

If you think your child is getting too much or not enough baclofen, you MUST take

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them to the emergency department and contact the Baclofen team.

How does the Baclofen get into the pump?

- On the face of the middle of the pump there is a silicon port (opening). A long, thin needle is used to inject the baclofen through the silicon into this port.
- A cream will be used on the skin over the pump to numb the area where the needle goes in. When the cream is used, most children do not feel pain from the needle. Some children will feel the pressure of the needle going through the skin.
- The procedure takes about 30-45 minutes in the outpatient clinic.
- The pump will need to be refilled every 2 to 6 months depending on the dose your child is receiving.

Follow-up

- The Nurse Practitioner (NP) in the Baclofen Pump clinic will be involved when you are considering the pump and throughout the implantation process.
- Your child will have a follow-up appointment with the NP within one week of being discharged from the hospital and then weekly. Your child's dose of Intrathecal Baclofen will be increased during each appointment until the optimal dose and effect is achieved.
- Your child will also have an appointment with his/her Neurosurgeon 3-4 weeks after surgery.
- Your child will have regular follow-up appointments with the NP for refills of Baclofen.
- The NP is also available if you have any other concerns in between regular follow-up appointments.

Important Considerations

- Your child should carry an identification card about his/her baclofen pump at all times.

- If your child needs an MRI (Medical Resonance Imaging) scan you must tell the MRI staff that he/she has a pump in place. The MRI machine can stop the baclofen pump from working during the scan. The baclofen team should be present to check the pump and make sure it has restarted after the scan.
- The pump will 'beep' when the battery is low or if the pump is close to running out of baclofen. If you hear beeping you must contact the baclofen team as soon as possible.
- The battery in the pump should last 6-7 years. This means your child will need another operation in about 6-7 years to replace the pump (if you decide to continue with the treatment).

Home Care Instructions

Skin Care

- Your child should not take a bath for 1-2 weeks. Sponge baths are recommended. After the incision is healed, it is OK for him/her to take a bath and gently wash the incision.
- Check the incision for any redness, swelling or drainage. Call your child's doctor if you see any of these.
- Your child should wear loose, comfortable clothing over the pump site while the incision is healing.

Activity

- Your child should restart physical therapy after going home. He/she should not do any twisting. Flexing at the hips and back should be limited.
- Flying on an airplane is OK, but you should let airport security know about the pump because it may set off security alarms.

Medications

- If your child is taking any other medication for spasticity (like oral baclofen) he/she should not stop taking it. If necessary, your child's doctor will give you a schedule

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for weaning this (coming off of medication slowly).

- Ask your child's doctor before you give your child any over the counter medications (such as cold or flu medications) because they may cause sleepiness.
- Be sure to let your child's other health care providers know that he/she has a pump, especially if he/she is scheduled for an MRI.
- Let the school nurse and teacher know that your child has a pump. They should also be taught what to do if there is a problem with the pump.

Pump Beeping

The pump is designed to beep if the amount of medicine in it gets too low or if the battery is running out.

- The battery in the pump should last about 6-7 years. Near the end of that time your child will have another operation to put in a new pump. If the battery starts to run out before the pump is replaced, the pump will 'beep'.
- If for some reason the pump is not refilled on time, the pump will 'beep' two days before the medicine is due to run out.

What to Do: If you ever hear beeping from your child's pump, you **MUST** contact the Baclofen team and take your child to the Emergency Department.

When to Call

Call your child's doctor if:

- The pump is beeping;

- You think your child is receiving too much or not enough baclofen (see side effects above); or if
- Your child has any of the following symptoms:
 - ❖ increased tightness of muscles
 - ❖ increased seizure activity
 - ❖ decreased tone
 - ❖ "floppiness"
 - ❖ fever (temperature higher than 101.5°F (38.6°C))
 - ❖ itchy skin all over
 - ❖ unexplained irritability
 - ❖ drowsiness (or you can't wake them)
 - ❖ nausea
 - ❖ vomiting
 - ❖ headaches
 - ❖ dizziness
 - ❖ trouble speaking or trouble seeing (blurry vision),
 - ❖ redness, swelling or drainage at the incision site,
 - ❖ swelling around the pump area.

Numbers to Call

If you are concerned about your child or have any questions, call 617-355-6369 and ask to page #7867 (PUMP) to reach the baclofen pump consultant on-call. A baclofen trained doctor carries this pager 24 hours a day, 7 days a week.

A [Spanish](#) version of this education sheet is available from your provider