BACLOFEN PUMP THERAPY
Baclofen Pump Program at Boston Children’s Hospital

PAGER:
617-355-6369 and ask to page #7867 (PUMP)
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What is spasticity?

Spasticity involves tight, stiff muscles that make movement — especially of the arms and legs — difficult or uncontrollable. It happens when there is an injury to a part of the central nervous system (the brain or spinal cord) that controls voluntary movements. Common conditions associated with spasticity include cerebral palsy, brain injury, stroke, multiple sclerosis and spinal cord injury. Spasticity can sometimes be very difficult to control and can get in the way of activities of daily living.

Treating spasticity may...
› Improve hygiene, activities of daily living and ease of care
› Improve gait and increase mobility
› Decrease spasm frequency, pain and fatigue
› Promote tone reduction and increased range of motion and joint position
› Complement other treatments, such as physical therapy, occupational therapy and speech therapy

What is baclofen?

The treatment of severe spasticity may require a combination of approaches. One of the most common treatments for spasticity is oral baclofen, which is a muscle relaxant. Although this works for many people, some may require high doses to effectively manage their spasticity. Higher doses may cause side effects, such as weakness, drowsiness and nausea. However, they still may not treat your child’s spasticity effectively. These patients may want to consider a baclofen pump.

What are the possible side effects of baclofen?

Side effects of baclofen may include:
› Constipation
› Urinary retention
› Weakness
› Nausea

What is a baclofen pump?

A baclofen pump is a little machine that is placed under the skin of one side of the abdomen (belly) near the hip bone. It is used to deliver intrathecal baclofen.

The pump is attached to a catheter (tube), which helps direct the medicine right to a specific area of the spinal cord (called the intrathecal space). This allows the medication to be delivered exactly where it works to help reduce the spasticity. When the same medication is given by mouth, only a tiny bit of it actually gets to the area where it works.

How does a baclofen pump work?

The pump delivers medication constantly throughout the day to help relieve spasticity. It can also be programmed to deliver different amounts of medication at different times of the day, if needed. A programmer (a very small computer) is used to tell the pump how much medicine to give. The programmer used telemetry (similar to radio waves) to communicate with the pump.

Once the pump is implanted and the dose is increased gradually to a level that is working for your child, there will be a notable improvement in their spasticity and comfort. There are no major limitations on activities once the surgery site is healed. Patients can still do the things they were doing previously.
The evaluation for getting a baclofen pump

If your doctor recommends a baclofen pump for your child, you will meet with the baclofen pump nurse practitioners and learn about the baclofen pump to make sure it is appropriate for your child.

From there, the baclofen pump nurse practitioners will help schedule an appointment with a neurosurgeon. You and your child will meet with the neurosurgeon to discuss the baclofen pump further and plan for the surgery.

Baclofen pump therapy is not suitable for every child, so a trial helps you and your doctors decide if it’s right for you. Having a trial does not mean your child will definitely get a pump as there are many influencing factors. All of them will be discussed with you before any decision is made.

What does the baclofen trial involve?

1. A physical therapist will examine your child in the morning prior to the procedure to learn their baseline level of spasticity.
2. Your child will have a local or general anesthetic and will be given an injection (called a lumbar puncture) of baclofen into the space surrounding their spinal cord. This happens in the operating room.
3. Your child should not have any pain during the procedure because of the anesthetic. During the day, your child may develop a headache. This can be a side effect of the lumbar puncture.
4. After the procedure, your child will go to a recovery room and nurses will care for and observe him or her while the effects of the anesthetic wear off. Side effects can include drowsiness, nausea and vomiting.
5. The baclofen will begin to work about two to three hours after the medicine is injected. At that time, a doctor and physical therapist will examine your child again to see if the baclofen has had any effect on your child’s muscles.

If the trial is successful and your child responds well to the baclofen, we will proceed with placement of the baclofen pump, usually the next day, if this is what you decide.

The trial is a single dose of baclofen and may have a significant effect on the tone (tension in the muscles) of your child’s legs. Remember, this effect may be more or less dramatic than the effect from the pump. This is because the pump dosing will be continuous and will be adjusted specifically for your child.
Baclofen pump placement surgery

If you and your child’s doctors decide that a baclofen pump is appropriate, the surgery is usually performed the day after the trial, unless a different plan is made. Surgery lasts about 1.5 to 2 hours. The length of surgery will be reviewed at your initial appointment with the surgeon. If your child has had a spine fusion, the procedure may last a little longer.

Your child will have to remain lying down in a bed for 24 hours to help prevent headache. After that, your child can get out of bed once they get used to sitting up again. You child will stay in the hospital for two to five days after surgery, depending on how well they recover (pain, constipation, feeding tolerance, etc.).

Initially, the pump is programmed for a very low dose. The team will see your child on an outpatient basis every one to two weeks for small adjustments until the spasticity is improved.

Incision and pump area

Your child will have Steri-Strips (white tape strips) across the incision, which will fall off on their own. Keep them dry for the two weeks after surgery. If they don’t fall off, you may take them off two weeks after surgery. Your child may bathe, swim or get the incision wet after two weeks if the incisions are healed.

For a few days to weeks after surgery, your child may have some swelling around the top and sides of the pump. This is from fluid and it is normal. An ace wrap or abdominal binder around the belly helps provide pressure to limit the swelling and to improve comfort. Your child should wear the binder for six to eight weeks after surgery.

If you notice any drainage from the incisions or any redness, contact the Baclofen Pump Team on call through the hospital pager at #7867 (PUMP).

Surgery after-care

Activity

Limit extreme bending, twisting or turning at the waist for six weeks. This limits stress on the incision and helps the catheter heal into place in your child’s back. Regular activities are fine.

Flying on an airplane is OK, but you should let airport security know about the pump because it may set off security alarms.

Medications

You may give your child acetaminophen (Tylenol®) every four to six hours for pain if needed.

Never stop anti-spasticity medicines like baclofen or Dantrium suddenly. This can cause withdrawal symptoms and may lead to illness. These medicines need to be stopped slowly. Once your child has a good result from the pump (which may take a couple of months), we will make a plan to begin weaning the oral baclofen.

Constipation

Constipation will sometimes get worse due to intrathecal baclofen. Your child should have a bowel movement at least every two to three days. Keep your child on their bowel medicines if they use them. Ask your child’s doctor for help with this if needed.

School

Your child should be able to return to school within a week after coming home from the hospital. The school nurse will not need to address the pump but may need to reposition the binder to ensure it remains in the correct position in the first couple of months after surgery.

Coordination with other health care providers

Be sure to let you child’s other health care providers know that he or she has a pump.

Pump Information

Always carry the emergency card and plastic guide that will be mailed to you after the surgery by Medtronic. This card will inform emergency personnel of the pump.

Surgery follow-up appointments

Appointments will be scheduled with the baclofen pump nurse practitioner every one to two weeks to adjust the dose of baclofen given through the pump until optimal dose and effect is achieved. An appointment will be scheduled with your neurosurgeon about four weeks after surgery to check the incision and ensure proper healing.
Baclofen pump FAQs

What are some of the possible complications of a baclofen pump?
These possible complications include:

› Risk of a bad reaction to anesthesia
› Risk of bleeding
› Risk of infection of the pump, catheter or wound (from surgery)
› Mild changes in bladder control (usually temporary)
› Overdose (too much) of baclofen
› Under-dose (too little) of baclofen
› Catheter kink (bent tubing) preventing the flow of baclofen
› Catheter break causing a baclofen leak
› Catheter disconnection from the pump, preventing baclofen from reaching the spinal cord
› Implant or pump failure or malfunction

What is the battery life of a pump?
The battery in the pump lasts seven years. Prior to that, your child will need another surgery to replace the pump. We will help keep track of when this will need to happen. In most cases, it is a much simpler surgery for the patient as they are used to the pump being there already.

Can my child get too much baclofen?
Overdose is rare. Children can get too much baclofen when a catheter is kinked and then becomes unkinked. This can also 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.

› Call 617-355-6369, Pager #7867 if
  • Their muscles are too loose
  • They feel drowsy
› Call 911 if
  • They have slow or irregular breathing
  • You cannot wake them

Can my child get too little baclofen?
After a short time, your child’s body will become dependent on 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 if the pump becomes empty.

Signs that you child may be in withdrawal from baclofen:

› Muscles are tighter than usual and not relaxing
› High temperature
› Itchy skin
› Irritability (grumpiness)

If you are concerned about withdrawal, page the baclofen pump pager at 617-355-5369, pager #7867 (PUMP).
Baclofen refill procedure

Your child’s baclofen pump will need to be refilled every two to six months depending on the dose your child is receiving. On the front of the pump, there is a silicon port (opening) in the middle. A long, thin needle is used to inject the baclofen through the silicon into this port.

The baclofen pump refill procedure will take place in a clinic at Boston Children’s Hospital or a Boston Children’s Hospital satellite clinic. The entire visit will take 30 to 45 minutes.

1. The skin over the pump will be numbed so your child will not feel the needle stick. The numbing cream is put on at home and should stay on for at least 60 minutes before the procedure starts.

2. The area over and around the pump will be cleaned with a topical antiseptic solution to eliminate any germs in the area.

3. A special paper drape is placed over the abdomen with an open circle to expose the pump. A small plastic template is placed on the pump to help locate the refill port.

4. A needle is inserted into the port of the pump. The old medicine in the pump is replaced with new medicine. The numbing cream used earlier will prevent your child from feeling any pain.

5. Once the refill is complete, a device is used to program the pump to indicate that it has been filled with new medicine. The device will also report when the next refill is due.

6. The nurse practitioner will schedule another refill appointment for your child before you leave.

We keep track of when your pump needs to be filled. If you need to change a refill visit, contact your nurse practitioner immediately. You must reschedule the visit when you call. If you miss a refill visit, your child could have withdrawal symptoms and require hospitalization.
PAGE THE BACLOFEN PUMP TEAM IF YOUR CHILD HAS ANY OF THE FOLLOWING SYMPTOMS:

› Increased tightness of muscles
› Floppiness
› Fever (temperature higher than 101.5°F or 38.6°C)
› Itchy skin all over
› Unexplained irritability
› Drowsiness (or you can’t wake them)
› Nausea
› Vomiting
› Headaches
› Dizziness
› Redness, swelling or drainage at the incision site
› Swelling around the pump area

You should also page us if you think the pump is beeping or if you believe your child is receiving too much or too little baclofen.

PAGER:
617-355-6369 and ask to page #7867 (PUMP)

Baclofen pump team

Kristin Buxton, MS, RN, CPNP
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The Baclofen Pump Team at Boston Children’s can be reached through the hospital operator at pager #7867 (PUMP) in case of emergency. A baclofen pump team member carries this pager 24 hours a day, 7 days a week.

For pump-related questions that can wait until the next day, you may contact the baclofen pump nurse practitioners at the numbers above during business hours.

Referrals to other families and patients with pumps are always available at your request.