

Neuromodulation

Intrathecal Baclofen Therapy



Information for patients

Bring this booklet with you to your family doctor appointments and to all of your appointments at the Neurosciences Ambulatory Clinic (NAC).

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Contact information

Clinic Nurse: _____

Booking Clerk: Ext. _____

You were seen in the Neuromodulation Program at the Neuroscience Ambulatory Clinic (NAC) to find out if Intrathecal Baclofen Therapy is a good option to help manage your spasms. This handout will give you information on the next steps.

If you have questions or if you have not received your follow-up appointment(s) within 4 weeks, please call the Neuromodulation Office at 905-521-2100, ext. 44591.

Doctors involved in my care:

Physiotherapists:

Nurses:

If there is a Substitute Decision Maker involved in your care, make sure that they attend all appointments with you to learn about getting and managing an intrathecal baclofen pump.

Hamilton Health Sciences and St. Joseph's Healthcare – Hamilton –retail pharmacies

The retail pharmacies at Hamilton Health Sciences and St. Joseph's Healthcare Hamilton – King Campus will **always** have baclofen and refill kits in stock.

The pharmacies are listed below:

- Hamilton General Drugstore
Hamilton General Hospital
Main Lobby
237 Barton Street East
Hamilton, Ontario

Phone: 905-577-8259
FAX: 905-577-8257
- McMaster Drugstore
McMaster University Medical Centre
Main Lobby
1200 Main Street West
Hamilton, Ontario

Phone: 905-521-5019
FAX: 905-521-4984
- Scripts Pharmacy
St. Joseph's Healthcare Hamilton – King Campus
Main Lobby
2757 King Street East
Hamilton, Ontario

Phone: 905-522-1155, ext. 34850
Fax: 905-573-4851

Baclofen

Baclofen is a medication used to help relieve spasms, pain and tightness of muscles. This medication can help people with multiple sclerosis, spinal cord injuries, cerebral palsy and other nerve and muscle conditions. It can be taken as a pill (oral medication) or delivered in a liquid form into the spinal fluid using catheter and a baclofen pump (Intrathecal Baclofen Therapy).

Many people can control their spasms well enough with oral medication, but some find that this treatment does not work well enough or that they have intolerable side effects.

Consider Intrathecal Baclofen Therapy if:

- You are not getting enough relief from other treatments for spasms.
- You are struggling with side effects from the oral medication, such as drowsiness, confusion, weakness and nausea.

What is involved with Intrathecal Baclofen Therapy?

If you choose Intrathecal Baclofen Therapy you will need to:

- ✓ Have surgery to implant the baclofen pump under the skin of your abdomen.
- ✓ Keep the pump full of baclofen at all times. Running out of medication in your pump will cause you to have symptoms such as seizures or rigid muscles, and you will need to go to the Emergency Department. See page 16 for more information.

Once Intrathecal Baclofen Therapy has started, it is very important that you **attend all appointments for pump refilling.**

How often you need to refill your pump depends on the amount of medication you need, but it is generally every 3 to 4 months once you have reached the right concentration level.

Never stop this medication suddenly.

What are the next steps?

If you and the team decide that intrathecal baclofen may be beneficial to you, you will then begin the trial and planning phase.

After this visit, here are the next steps at a glance:

1. A visit with the psychologist.
2. Test dose of intrathecal baclofen.
3. Assisting with funding for drug coverage.
4. A visit with the neurosurgeon.
5. A Pre-op Clinic visit located at 690 Main Street West, Hamilton (same building at the Urgent Care Centre).
6. Surgery to insert a permanent pump.
7. An appointment to remove the sutures 10 to 14 days after surgery.
8. A follow-up appointment with your surgeon after your surgery.
9. Several appointments over the next 2 months at the NAC. This could range from 2 to 4 visits or more. During this time you will be gradually switched from oral baclofen (pills) to using the pump only.
10. Refill visits approximately every 4 months. There is a cost of the refill kit.

Step 1 – Psychology Appointment

Before you decide to have the therapy, you must attend a visit with one of our psychologists. The psychologist will help you determine if Intrathecal Baclofen Therapy is right for you. For example, if you are ready for this commitment and if you have other issues, such as financial, that may impact the long-term success of this therapy.

Setting realistic goals with your health care team is key to the success of this treatment.

Step 2 – Test dose of baclofen

This is the trial phase for intrathecal baclofen to see if this treatment will work for you.

Day of your procedure

Please bring your health card, wheelchair or any other aids you use every day to the Hamilton General Hospital. Your family or a support person can stay with you the whole day. Lunch is provided but you may wish to bring in snacks or activities.

When you arrive at the hospital, go to Patient Registration on the Main Level. From there you will go to 7 West. You will be admitted for the day.

During your procedure

The doctor will perform a lumbar puncture to inject a small dose of baclofen into the space where fluid flows around your spinal cord.

You will spend the day with the physiotherapist completing many different assessments looking at your spasms and function. These assessments will be done before the injection and then at 1, 2, 4 and 6 hours after the injection.

The physiotherapist will videotape these assessments and share the videotape with the health care team.

Going home

You will be at the hospital for at least 6 hours. The baclofen injection generally wears off in about 6 hours. You may stay up to 8 hours or until it is safe to go home.

Watch for signs and symptoms of a headache after your procedure.

Headache after your procedure

You may develop a headache during the first few hours to a few days after your procedure that may last for several days. The headache may be mild to severe and may get worse when you sit or stand and get better when you lay flat. These tips may help to ease a headache:

- **Drink plenty of liquids:** Drink more liquid than usual after your procedure. Ask how much liquid is right for you.

Caffeine may be used to treat a headache. Drinks, such as coffee, tea, or some sodas have caffeine. Caffeine is also available over the counter in tablet form. Ask about using caffeine to treat your headache. Do **not** drink alcohol.

- **Acetaminophen (Tylenol®):** You may take as directed for headache if not taking any other medications that contain acetaminophen (too much acetaminophen can cause liver damage).
- **Lie down:** If you have a headache after your lumbar puncture, it may be helpful to lie down and rest.
- **Call:** 905-521-2100, ext. 44591 if your headache is severe or the headache lasts longer than 2 days. If unable to reach the Neuromodulation Team, call your doctor.

Go to the Emergency Department or call 911 right away if:

- You have a severe headache that does not get better after you lie down.
- You have a fever (38.5°C or 100°F) and chills.
- You have a stiff neck or have trouble thinking clearly.
- Your legs, feet, or other parts below your waist feel numb, tingly or weak.
- You have bleeding or a discharge coming from the area where the needle was put into your back.
- You have severe pain in your back or neck.
- You have increasing pain at the incision site.

Step 3 – Applying for funding

The cost of the baclofen pump is covered by OHIP. However the cost of the baclofen medication used in the pump is not covered and is an ongoing cost, just like other medications you may be taking.

Some insurance companies cover intrathecal baclofen as they do other prescription medications. You will need to contact your insurance company.

Intrathecal Baclofen Drug Identification Numbers	
02131048	Lioresal™ Intrathecal 0.05 mg/ml
02131056	Lioresal™ Intrathecal 0.5 mg/ml
02131064	Lioresal™ Intrathecal 2 mg/ml
02413620*	Val-Baclofen 0.05 mg/ml
02413639*	Val-Baclofen 0.5 mg/ml
02413647*	Val-Baclofen 2 mg/ml

* The Exceptional Access Program (EAP) will now only reimburse the cost of the generic drug (the Val-Baclofen).

Please note that for all **new** (EAP) requests, the Val-Baclofen drug identification numbers should be used. The Lioresal product will not be reimbursed.

For existing EAP's, we will continue to supply the Lioresal™ product.

If you do not have medical insurance coverage, our team can apply for the EAP. If successful, this program will cover the cost of the drug. However, you must pay for the refill kits each time you get a refill. The kit costs approximately \$50.00.

Step 4 – Neurosurgery appointment

If the test dose was successful, you will be given an appointment to see the neurosurgeon. At this appointment, the neurosurgeon will assess and determine whether surgery is right for you. If so, the neurosurgeon will discuss the surgery with you and ask for your consent.

Step 5 – Pre-op Clinic visit

You will be given an appointment at this visit for a Pre-op Clinic visit at 690 Main Street West, Hamilton (same building as the Urgent Care Centre). Every person going for a procedure at Hamilton Health Sciences is seen at the Pre-Op Clinic.

Step 6 – Surgery for the pump

The night before your surgery

You may eat or drink until 12:00 midnight the night before your surgery.

The day of your surgery

The Pre-op Clinic will give you instructions on what medications you may take the morning of your surgery. Take with only a sip of water.

Bring:

- All of your current medications in their original containers.
- Comfortable walking shoes.
- Loose fitting clothing.

Leave money, credit cards, jewelry and valuables at home. Bring your wheelchair to the hospital. The neurosurgeon will look at how you sit in the wheelchair to decide where to place the pump in a comfortable position into your abdomen.

When you arrive at the Hamilton General Hospital, go to Patient Registration on the Main Level.

After you have registered, you will go to the Same Day Surgery on the 3rd floor. You will be asked to change into a hospital gown. An intravenous line (IV) will be started in one of your hands.

During your surgery your family may wait in the 3rd floor waiting room. The neurosurgeon will speak to your family after your surgery is done.

During your surgery

You will be sleeping. A catheter is inserted into your spinal column and guided to your abdomen. The pump is the size of a hockey puck and placed in your abdomen.

The surgery will last 1 to 2 hours.

Going home with the insertion of the intrathecal pump

Expect to have some pain at the incision in your abdomen.

Do not reduce your regular pain medications or baclofen unless told by your doctor or nurse.



You will need to make an appointment with your family doctor to remove the suture about 10 days after your surgery.

Incision care

- Keep the incision clean and dry. **Do not shower or bathe.** You may take a sponge bath. You may shower after sutures have been removed.
- Do take your antibiotics.
- Watch the insertion site for signs and symptoms of infection. Signs of infection are:
 - redness or heat around the incision
 - green, yellow or white drainage from your incision
 - opening of your incision
 - fever (38.5°C or 100°F) and chills
 - Increase in spasms

Activity

- When caregivers help you to turn, make sure that they **do not pull** on the area of pump or spinal catheter. Turn using your hips and shoulders where possible.
- You may return to your normal activities such as getting up in your wheelchair.

Step 7 – Follow-up visits at the NAC

You will come back for a follow-up visit with the neurosurgeon at the NAC after your surgery in two weeks.

Step 8 – Device monitoring, ongoing care and refills

After your surgery, your pump is working. We will slowly increase the amount of baclofen in your pump over a few visits. During this time, we will also decrease the amount of oral baclofen (pills) that you take.

In the beginning it may seem like a lot of appointments. The appointments become less often once the neurosurgeon tells you to stop taking your oral baclofen (pills).

You will have to come back to have baclofen refilled in your pump on a regular basis. The pump is refilled by putting a needle through your skin in your abdomen into the refill port on the pump. The appointment to refill your pump takes about 30 minutes. You will need to pick up your refill kit and medication at the pharmacy and bring to your appointment.



The patient and/or caregivers are responsible to always know when the pump will empty.

The doctor will give you a date of your next refill. You must remember that date and keep your appointment as running out of baclofen could be life threatening.

For more information see page 16.

Replacement of pump

The pump will work for about 80 months (6 ½ years). At each appointment the health care team will tell you the Estimated Replacement Time or ERI of the pump.

At that time, you will need to have surgery to insert a new pump. If the catheter is still working and in good condition, then it will not need to be replaced.

Pump alarms

The pump will alarm if it needs to be refilled, malfunctions or if the battery reaches end of service. There are 2 types of alarms:

1. A non-critical alarm with a single tone beep. This alarm goes off once an hour.
2. A critical alarm with a two tone beep. This alarm goes off every 2 minutes.



When the alarm goes off on your pump, go to the Emergency Department right away.

Special precautions if you ever have had an MRI

During an MRI your pump motor will stop. Once you are removed from the MRI machine, the pump generally goes back to working normally. However, you must wait about 30 to 45 minutes after your MRI for the technologist to check your pump to make sure it has started to work again.

If you need to have an MRI for any reason, have it done at the Hamilton General Hospital as the technologists are familiar with the pump and know how to check it. Your neuromodulation team is also at this site and available to help if needed.

Important!



If you move or change phone numbers, or if you get a new family doctor, please call the clinic to let us know any changes. This is important for future appointments and so that we can contact you if we learn of any problems with your pump from the manufacturer.

Go to the nearest Emergency Department or call 911 if you have ...

- Confusion
- Drowsiness
- Dizziness
- Seizures
- Difficulty breathing
- An increase in spasms
- Rigid muscles
- Passed out or are in a coma
- Fever (38.5°C or 100°F) and chills

Call the Neuromodulation Team Specialist if:

- You have changes in your spasms.
- You have any questions.


