Going Home After Neurostimulation

Read this pamphlet to learn about how to take care at home after your neurostimulation surgery:

• How to take care at home
• What signs of infection to watch for
• What to do in case of emergency
• When to expect a follow up visit

Krembil Neuroscience Program
What do I need to know about recovering at home?

Incision care
Your incisions will have staples or stitches and will be covered with bandages (dressings).

You will need to remove the bandages 4 days after your battery is inserted in your chest, abdomen (belly) or buttock.

After the bandage is removed:

• Leave the bandage off, if you prefer.
• Keep the incision site clean and dry. Do not apply creams, lotions or ointments to the area.
• Keep your head covered by wearing a clean scarf or a loose-fitting hat when you go outside. Make sure you wash anything you wear over your head frequently in hot water.
• Never touch, scratch or apply any pressure on the incision sites.

Make an appointment to see your family doctor 10 to 14 days after your last surgery to have all your staples or stitches removed.

Date:______________________________________________________.

We will give you a staple/stitches removal kit when you are discharged from the hospital. Make sure to bring the staple remover with you when you see your family doctor.
Hygiene (showering and bathing)

- You can take a shower and wash your hair and body with mild soap or shampoo **4 days** after your last surgery.
- Do NOT soak your incisions in water for the first **12 weeks** after your surgery.
- Do not swim or use a hot tub for 12 weeks.
- Make sure your hats, bed linen, pillows and wigs are clean.
- Stop pets from going close to your incisions and wash your hands well after touching them.
- Wash your hands often.
- If you have a scalp incision, do not dye your hair for at least 12 weeks after your surgery. You can use a hair dryer once your scalp staples or sutures are removed.

Your activity

- Do NOT lift anything heavier than 5 pounds (or 2.5 kilograms) for 12 weeks.
- Avoid strenuous activity for 12 weeks.
- Do NOT do any activity that could overheat your stimulator (using tanning beds, hot tubs, saunas and steam rooms) until your incision sites are completely healed.

After 3 weeks, you can start to increase your activity level gradually as much as you can handle.

Please talk with your neurosurgeon about these or other activities that you are not sure about, such as traveling or returning to work.
# Watch for these signs of infection

Look at your incisions every day and watch for these signs of infection:

<table>
<thead>
<tr>
<th>Signs of infection</th>
<th>What to do</th>
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</thead>
<tbody>
<tr>
<td>• Increased redness or swelling at your incision site</td>
<td>• If you notice <strong>any</strong> of these signs or symptoms, go to your family doctor or nearest Emergency Department on the same day.</td>
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<tr>
<td>• Leaking (for example with yellow or green-like pus) from your incision</td>
<td>Please also tell your neurosurgeon, nurse coordinator or nurse practitioner as soon as possible.</td>
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<tr>
<td>• Bleeding from your incision</td>
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<td>• Pain at your incision site that does not go away</td>
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<tr>
<td>• Fever (a temperature over 38 °C or 101 °F)</td>
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<td>• Opening of the incision edges</td>
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<tr>
<td>• Incision site is warm or hot to the touch</td>
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When to go to the Emergency Department after surgery or programming

• Any sudden, unexpected change in your health
• A seizure
• Signs of infection
• Signs of stroke
• Sudden severe change in thinking, such as confusion, hallucinations, or memory loss
• Sudden change in mood, especially depression or any strange behaviour
• Thoughts of suicide or urge to hurt others

When the battery is getting low

• You will be referred to a Neurosurgeon to replace the battery. This will be done at the hospital and you can leave the same day.

• If you have a Medtronic DBS system, please call the clinic if it says “ERI” because it means your battery is getting low and has about 3 months of battery life left. **If it says “EOS” your battery will need to be replaced right away.**

• Your Neurosurgeon’s office will send you forms for your family doctor to fill out. They will arrange for you to have blood tests, an echocardiogram (ECG) and chest x-ray at the hospital. You will also see the anesthesia doctor.

• If you do not live near the hospital, they will give you a requisition to have these tests done in your community.

• You may need to see your Neurosurgeon to sign a consent form for surgery.
Changing the battery

• The Neurosurgeon will replace the battery during surgery. After surgery, you will go to the Day Surgery Unit for a short period of observation.

• A member of the Movement Disorders or Neurosurgery team will program your battery with the stimulation settings you had before the battery was changed.

• You will go home the same day, usually within 4 hours.

Some batteries are rechargeable and can last 9 years or longer.

If you have a rechargeable battery, you must recharge it regularly to avoid depleting the battery too much. The amount of time for charging depends on the settings used in your battery.

What do I need to do to stay safe with a DBS/SCS system?

Please follow these rules for your health and safety.

Always carry your DBS/SCS Registration Card

• Before you leave the hospital, you will get a temporary registration card for your DBS/SCS system from the company that makes it. A permanent card will be mailed to you. Please allow 12 weeks to receive the card in the mail. Carry this card with you at all times.
Tell all your health care providers that you have a DBS/SCS system

- All your health care providers need to know that you have a DBS/SCS system implanted in your body so they can take steps to keep you safe.
- Consider getting a Medic Alert bracelet. In an emergency, the bracelet tells medical staff that you have a DBS/SCS system.

NEVER apply heat to your DBS system

- Do not put heat on any part of your DBS/SCS system as this could damage it and harm you.
- Do not have diathermy treatments (heat therapy), which deliver energy to heat and heal tissues in your body.

Check with your doctors before having an MRI

The safety of having MRI of your brain or body depends on the type of DBS/SCS system you have and the MRI services. This chart is a general guide.

<table>
<thead>
<tr>
<th>DBS/SCS Manufacturer</th>
<th>Head MRI</th>
<th>Body MRI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medtronic – Old systems</td>
<td>Only allowed at Toronto Western Hospital</td>
<td>Not allowed</td>
</tr>
<tr>
<td>Medtronic – New systems</td>
<td>Allowed in any radiologic service but with restrictions</td>
<td>Allowed in any radiologic service but with restrictions</td>
</tr>
<tr>
<td>Boston Scientific</td>
<td>May be allowed with restrictions</td>
<td>May be allowed with restrictions</td>
</tr>
<tr>
<td>St. Jude Medical</td>
<td>Not allowed</td>
<td>Not allowed</td>
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</table>

Your device will need to be turned to MRI mode when you go for this test. Please tell your health care practitioner if you have a MRI booked.
Check with your doctor or the manufacturer of your device before having other medical procedures

Most medical procedures are safe (such as a CT scan, ultrasound or x-rays), but some need extra precautions, and others are not possible because they could cause serious harm or death.

Frequently asked questions by patients about their DBS/SCS

Can I use household electrical appliances if I have DBS/SCS?
Yes. Using everyday electrical and electronic devices does not affect how your battery works.

Will I feel the electricity in my body when the IPG (battery) is working?
Some people might have a tingling feeling for a few seconds after the device is turned on, but this goes away within seconds.

Will my battery activate metal detectors at the airport?
Yes, it will set off the alarm and the security equipment may turn the neurostimulator off. Please show your medical card to the airport staff and they will take the necessary precautions.

What if I need electrical shock for resuscitation?
If you need heart resuscitation, it should be done. The most common result is that the battery might get damaged and will need to be replaced.
What happens if I need a heart pacemaker?
You can have both a DBS/SCS system and a heart pacemaker. Both devices can work without interfering with each other. Tell your surgeon or cardiologist that you have a DBS/SCS system implanted.

Can I do my own programming?
Finding the right contact on your DBS/SCS lead can only be done by the DBS neurologist or the nurse practitioner who will be doing the programming for your DBS or SCS.

What is a Patient Programmer?
A patient programmer is a small device that comes with your neurostimulator. It lets you turn your stimulator on and off and make other adjustments once your system is turned on and programmed.

You will be shown how to use your programmer during your follow up visit with the neurologist or neurosurgeon or before your discharge from the hospital.

DO NOT try to use it until your neurostimulator has been turned on and you have been shown how to use the programmer.

Please remember to bring your programmer with you to every follow up appointment.

Taking your medications
Talk to a member of the health care team before you start taking any blood thinners again that you were on before your surgery (for example Coumadin, Aspirin, Plavix, Apixaban, Rivaroxaban).

Keep taking all your other medications as before your surgery unless your health care professional tells you not to.
How can I cope with pain?

• You may have a headache or pain around the incision sites. This should slowly get better.

• Your doctor may give you a prescription for pain medication when you leave the hospital. Take pain medication when you need it and follow the instructions on the package.

• If you had a stimulator inserted for pain and your pain decreases, see your family doctor or pain specialist about decreasing your pain medications. You should not stop any pain medications abruptly.

• DO NOT take acetylsalicylic acid (Aspirin) or ibuprofen (Advil) for pain.

Follow-up visits

• Arrange an appointment with your family doctor to remove your staples **10 to 14 days** after your surgery.

• We will give you a follow-up appointment with your neurosurgeon about **4 to 12 weeks** after your first DBS/SCS surgery. If we have not called you with an appointment within 2 weeks after surgery, please call your neurosurgeon’s office to make a follow up appointment.

• If you are a patient of the Movement Disorders Clinic, your next appointment for initial programming is **6 to 8 weeks** after your surgery. Please do not take PD or tremor medications after midnight the day before programming appointments.

• If you are having your battery replaced your settings will be programmed the same day of the surgery and you will keep your usual follow-up schedule.
Where to get more information

If you have any questions, please ask a member of your health care team during your appointments or give us a call.

Neurologists
Dr. Fasano        Phone: 416 603 5800 ext. 5729
Dr. Munhoz

Neurosurgeons
Dr. Lozano        Phone: 416 603 6200
Dr. Hodaie        Phone: 416 603 6441
Dr. Kalia         Phone: 416 603 5866

Nurse Practitioners
Alex Valencia     Phone: 416 603 5800 ext. 2356
Alina Mednikov    Phone: 416 603 5800 ext. 2288
Darcia Paul       Phone: 416 603 5800 ext. 6141

DBS Nursing Line  Phone: 416 603 5800 ext. 2356

Administrative staff
Cecilia Miraldo   Phone: 416 603 5800 ext. 5729
Prasha Sasitharakumar
Anna Robitaille

For technical questions about your DBS/SCS or about medical procedures:
You or your doctors can also call the customer service of the manufacturer of your device.
For more information about preparing for DBS, surgery, hospital stay and recovery at home:
Please refer to pages 13 – 26 of the UHN “Deep Brain Stimulation” patient education manual given to you at your first appointment.

Notes

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