

## The Spasticity Clinic

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This booklet can help you learn about:

- the Spasticity Clinic at McMaster Children's Hospital
- spasticity and how it may be treated

Your therapist will give you more information and answer any specific questions you have about your child's treatment.

### What is the Spasticity Clinic?

The Spasticity Clinic helps children with spasticity and their families. Care at the clinic is provided by a team of health care providers including:

- doctors who specialize in caring for children and teens with spasticity
- a physiotherapist
- an occupational therapist
- a registered nurse
- a child life specialist

You, your child and family will work closely with team members to find out why your child has spasticity and what kinds of treatment may help. Your child's therapist(s) is/are welcome to come to your clinic visit. Our team will also work with your orthopedic surgeon, orthotist and local rehabilitation services.

You may also meet therapy students and doctors (called residents) who are learning how to help children with spasticity.

The clinic is a busy place, but we hope you will feel welcome and comfortable. Please feel free to ask questions at any time.

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## How can the Spasticity Clinic help you and your child?

Our clinic can help if spasticity affects:

- Motor skills**      • your child has problems with walking, sitting, using his or her arms or hands, or everyday activities
- Comfort**            • your child has pain when wearing braces, when sitting or sleeping, or has problems with skin sores or contracted muscles
- Posture**              • your child's position could lead to changes to the muscles or bones
- Caregiving**        • you have difficulty in lifting, positioning, bathing, diapering or dressing your child

## How can my child be referred to the clinic?

If you would like your child to come to the Spasticity Clinic, ask your doctor to fax a referral to **905-521-5056**. The clinic support staff will let you know the date and time of your visit.

## What happens during the clinic visit?

At your visit we will get to know your child. We would like to know what your child does at home and what has changed recently. We will assess how well your child can move and use his or her muscles and joints. Please bring your child's walking aids and braces.

After the assessment, we will discuss the choices for treatment. With your permission, we will send a report to your local therapist after the visit.

Your child may return for other visits, if more assessments are needed.

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## What is spasticity?

Spasticity is the medical term that describes muscles that are:

- tight – too active and unable to relax
- stiff – too much tone or resistance

Everyone has some resistance in his or her muscles. This can be felt when the arms or legs are moved. However, when a person with spasticity moves, the resistance increases.

- The faster the arm or leg is moved, the greater the resistance.
- The slower the arm or leg is moved, the less resistance.

You may notice the spasticity increases when your child is working hard, is excited or is in pain, and it decreases when he or she is asleep.

Spasticity makes movement difficult. It can make it harder for your child to do daily activities (such as sitting, walking, playing, dressing, bathing) and learn new movements.

If the muscles do not move well, they become stiff. Over time, the muscles shorten, causing contractures to develop. Contractures are permanent changes in the muscles and joints that can affect your child's care and comfort.

## Why does this happen?

During activities such as walking, the brain sends many signals to the muscles. It tells some muscles to be active and tells others to relax. Spasticity occurs when the signals telling muscles to relax are blocked. The blockage is caused by damage to the nerves in the brain or spinal cord. This can occur with cerebral palsy, brain injury or spinal cord injury.

## What are the treatment options?

Although spasticity cannot be cured, treatments can reduce spasticity and improve your child's movement and comfort.

The choice of treatment will depend on:

- what you and your child prefer
- your child's age and developmental level
- the amount of spasticity and how it affects your child

**During the clinic visit we will discuss various treatments. More information is available at the clinic or from your own therapist.**

We may discuss treatment options such as:

- a therapy program, with everyday activities and exercise at home
- equipment to put your child's body in a better position
- casts to gradually stretch your child's muscles
- medications that your child takes as a pill or drink
- medications that we give your child with a needle
- surgery

**A combination of treatments may be the best choice for your child. Exercise and positioning are needed to get the best results from medication and surgery.**

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## Therapy program

Your child's physiotherapist or occupational therapist may tell you about exercises, activities and equipment that you can do or use with your child at home and in the community.

These are important for making spasticity easier on muscles, bones and joints.

Exercise and using equipment to position your child better can make your child's muscles stronger and loosen up his or her body. This will help your child do activities more easily.

## Positioning devices

Different pieces of equipment such as braces, splints, wedges and standers help to keep your child's muscles long and support joints. This can stop muscles from becoming contracted and help make movement easier.

The Assistive Devices Program (ADP) covers the costs of some positioning devices. Your own therapist or orthotist can give you more information about this program.

## Serial casting

Casts may be used on your child's arms or legs to make short muscles longer. The casts are left on for 1 to 2 weeks. More than one cast is often needed. Each one helps to lengthen the muscles a bit more.

The cost of casts is not covered by OHIP (Ontario Health Insurance Plan).

A drug plan (your own health insurance) or social assistance may pay for the costs.

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## Medications

If taking medication is part of your child's treatment, a doctor needs to regularly check how well the medication is working and watch for side effects. Side effects are possible with all medications.

Please tell the clinic doctor:

- all medications (prescription and over-the-counter), vitamins, supplements and herbal remedies your child is taking
- any health problems your child has such as lung, heart and liver disease

The health care team at the clinic will give you more information about the medications prescribed for your child.

### Medications by mouth

These medications help to relax muscles:

- Baclofen (Lioresal<sup>®</sup>)
- Diazepam (Valium<sup>®</sup>)
- Tizanidine (Zanaflex<sup>®</sup>)
- Dantrolene (Dantrium<sup>®</sup>)

These medications help to decrease movements that your child cannot control (involuntary movements):

- Trihexyphenidyl (Artane<sup>®</sup>)
- Dopamine (Sinemet<sup>®</sup>)

### Medications with a needle (injections)

These medications can be given with a needle, to target specific muscles.

- Botox<sup>®</sup> (Botulinum Type A Toxin)
  - Ethanol Nerve Block
  - Intrathecal Baclofen
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## **Botox®**

Botox® is a substance made by bacteria. It is purified so it can be safely used to relax muscles. When a tiny amount of Botox® is injected, it blocks a chemical signal between the nerve and muscle. This prevents the muscle from contracting and relieves spasticity.

### **How does the treatment work?**

- Botox® is injected right into the spastic muscle. It only affects this area. It does not go anywhere else in the body.
- When the spastic muscle becomes relaxed it can be stretched out. This helps the muscle to grow and get longer with therapy.
- Botox® takes 1 to 3 days to start working. The best results are felt in 1 to 2 weeks and can last in the muscle several months.
- The effects of Botox® are temporary. Your child may need lots of injections to get the greatest benefits.

### **How can Botox® help my child?**

Each child reacts differently to Botox®, but here are some possible benefits:

- your child is able to move better, and his/her arms and legs are able to move more easily
- your child is able to do everyday activities better
- your child is more comfortable in his/her braces and wheelchair
- your child is easier to take care of
- it may make serial casting more comfortable and work better
- it may stop or put off needing orthopedic surgery

**To get the best effect of the Botox® injection,  
your child should have a therapy program as well.**

**What are the complications of Botox®?**

Complications do not happen often. Here are some possible complications:

- soreness from the injection
- bleeding and infection where the Botox® was injected
- fever from the injection
- an allergic reaction
- although it is very rare, the Botox® may affect other areas of the body

**What happens after the Botox® injection?**

- Do not rub the skin where the Botox® was injected that day as these areas may be a little sore. Also, rubbing may cause the Botox® to move into other areas.
- Your child can do everything he or she normally does, including walking around or showering.
- You do NOT have to give your child acetaminophen (Tylenol®).

**How much does it cost?**

- Each vial costs around \$400. Up to 4 vials may be used, depending on your child's weight and the number of muscles injected.
- The cost is NOT covered by OHIP. You may have a drug plan or social assistance that will pay for the cost. The health care team will talk about the different funds with you.

**Ethanol Nerve Block**

When ethanol is injected at a nerve, it strips off the layer of fat that covers the nerve at that spot. This makes messages from the nerve go more slowly. As a result, the spastic muscle that that nerve goes to relaxes. The effects can last 6 to 9 months.

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## **Intrathecal Baclofen**

Intrathecal baclofen refers to a method of putting the medication that relaxes muscles directly into the area around the spinal cord (called the intrathecal space).

In a surgical procedure, a small pump filled with baclofen is put under the skin of your child's abdomen. A thin, flexible tube called a catheter runs from the pump to the area around the spinal cord. The pump is programmed to deliver a prescribed amount of baclofen into this area.

At the moment, this surgery and follow-up are done at the Hospital for Sick Children in Toronto.

## **Surgery**

### **Orthopedic surgery**

Orthopedic surgery can correct the effects of spasticity. Your child may need surgery to:

- lengthen muscles or tendons
- change the angles of bones
- treat contractures to allow greater movement of joints

The aim of surgery is to improve your child's movement and make everyday activities and care easier.

### **Selective Dorsal Rhizotomy**

In this type of surgery, the nerve rootlets coming off the lower end of the spinal cord are cut. After they are cut, the messages from excited nerves in the legs cannot reach the brain. This permanently reduces spasticity, without affecting sensation. This surgery is not done in Ontario at the moment.



## Questions



If you have any questions or concerns, please speak with any member of your health care team.

Please fax referrals to 905-521-5056.

## More information



You can find more information about spasticity at the website for CanChild, the Centre for Child Disability Research.

[www.canchild.ca](http://www.canchild.ca)

