

INFO SHEET



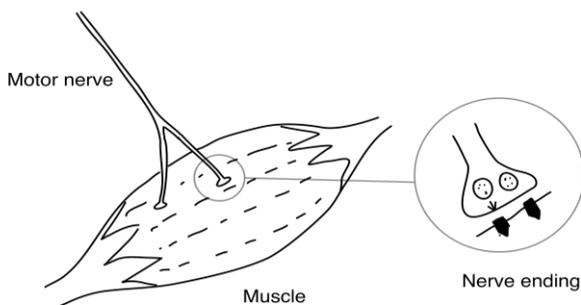
This info sheet is for education purposes only. Please consult with your doctor or other health professionals to make sure this information is right for your child. If you would like to provide feedback on this fact sheet, please visit: www.schn.health.nsw.gov.au/parents-and-carers/

Botulinum toxin type A (BoNT-A) injections

If your child has cerebral palsy, an acquired brain injury or spinal cord injury, your healthcare team may have recommended botulinum toxin type A injections. The brand names for these injections are Botox® and Dysport® and this leaflet refers to both as BoNT-A.

When muscles are stiff as a result of one of these conditions, BoNT-A can help relax the muscles, helping your child feel more comfortable. This information will help you make an informed decision about whether the injections are right for your child. Your child can't receive the injections without your consent.

How does BoNT-A work?



A dose of BoNT-A is injected directly into a stiff muscle to cause a temporary relaxation or softening of that muscle. This can be helpful if muscle stiffness is interfering with your child's abilities or is causing pain. BoNT-A attaches to nerve endings in a muscle and temporarily blocks the chemical messages between nerves and muscles that makes muscles tighten. This can help muscles relax.

It can take around two weeks for the effect of injections to take effect. The benefits may last between three and six months, after which time the injected muscle returns to its previous state and stiffness may return.

How is BoNT-A given?

Injections are given with a very fine needle, often using an ultrasound scan to help the clinic staff see the muscle clearly. The dose that is injected is carefully worked out for your child based on their weight. Several injections may be needed, depending on the number of muscles that are selected. Some children may require only one injection, while others may need up to 20. This is decided with you before the injections are done. The injections can take between 5 and 20 minutes. We encourage you to stay with your child during the injections and recovery, as a loving familiar face provides great comfort and reduce their worry. This will be different for children having a general anaesthetic - this information will be provided to you separately.

Are the injections painful?

Having several injections at one time can be unpleasant and painful for some children, so sedation can be offered for the injections. Some older children choose not to have any sedation so you can discuss this with the clinic staff. Your team will help you choose the best sedation for your child, and do their best to make the injections as comfortable as possible for them.

Types of sedation

As well as having an anaesthetic cream applied to numb the skin where the injections will be given, nitrous oxide is the most common sedation used during the injections. Different sedation options are available for your child and each one has different fasting and recovery times. These will be discussed with you.

1. **Nitrous oxide gas** (known as “happy/ laughing gas”) is a clear, odourless gas given through a face mask that covers the nose and mouth. Nitrous oxide sedation can be carried out in the outpatient clinic. As your child starts to breathe in the gas they will feel drowsy but they don’t become unconscious. Once the injections are finished, the gas is stopped. Because the gas wears off quickly; your child can eat, drink and return home as soon as they have fully recovered, usually within 5 to 10 minutes after they leave the clinic room.
2. **Midazolam** is given as a liquid for your child to swallow. It can be given by itself or as well as nitrous oxide sedation. Midazolam helps children be less anxious about the injections. You may be asked to stay for at least one hour from the time midazolam is given to allow your child to recover fully. Occasionally some children react to midazolam by becoming more anxious and active, so it is important to speak with the doctor about how it may affect your child.
3. **General anaesthetic (GA)**. If nitrous oxide gas or midazolam do not provide enough sedation for your child, a GA may be suggested. In this case, your child will need to be admitted to hospital as a day patient. Recovery is usually complete four hours after the procedure has finished.

Are there other options?

Using BoNT-A is not essential for children with stiff muscles. You can choose not to have this treatment. Other options for muscle stiffness are oral medications, serial casting, splinting and physical therapies. Feel free to ask your child’s healthcare team about alternatives.

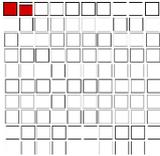
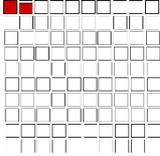
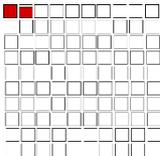
Preparing for the procedure

- The clinic staff will send you an information letter with the date for the injections so bring this with you on the day so you know where to go. Please read the rules for fasting and giving your child’s regular medication that will be written in the letter. These times must be followed as fasting is done to decrease the risk of nausea and vomiting during sedation. You can phone the number listed below if you have any questions.
- If you have been asked to bring a referral letter from your GP, please bring it on the day.

- As with many hospital appointments, you may have long waiting times so be prepared with things to do for your child such as books and activities.
- It is important your child is well on the day of the injections; if you are uncertain about this, check in with the clinic staff.
- Talk to your local therapists and let them know your child is having BoNT-A injections.

Risks during the procedure

The clinic staff will ensure the procedure is as safe as possible but like all medical treatments there are some risks.

	Frequency	Outcome
Distress	 <p>18 out of every 1000 children</p>	For children who become very distressed the sedation may be changed or the procedure cancelled.
Pain	 <p>17 out of every 1000 children</p>	This is usually due to bruising where the injection is done. The area usually heals.
Nausea and vomiting	 <p>17 out of every 1000 children</p>	Vomiting during the procedure can be dangerous as there is a risk of stomach contents getting into the airways and lungs. Please obey the rules about fasting to minimise this risk.

Less common risks that may occur from the injections include:

1. Bleeding – this is more common if your child is taking blood thinning medications. Please speak with your doctor about all medications your child takes.
2. Bruising, allergic reaction, or rash.

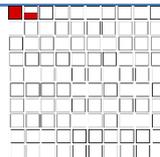
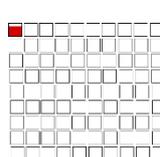
3. Infection – this may require treatment, including antibiotics.

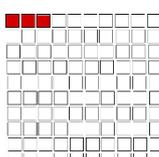
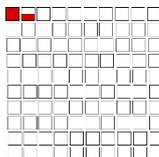
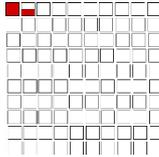
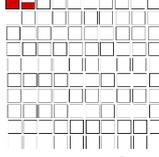
Less common risks that may occur during the sedation include:

1. Seizures – You can minimize this risk by ensuring your child takes their regular epilepsy medicine on the day of the injections.
2. Over-sedation and difficulty breathing.

After the procedure

A few weeks after the procedure, please get in touch with clinic staff to let them know how well the BoNT-A has worked and if your child has experienced any side effects. Side effects are not common, but can include:

<p>Bowel problems</p>	 <p>14 out of every 1000 children</p>	<p>This can include constipation or diarrhoea.</p>
<p>Generalised weakness</p>	 <p>7 out of every 1000 children</p>	<p>The effect of BoNT-A spreads to muscles that were not injected and causes unexpected weakness.</p>

Frequency	Outcome
<p>A flu-like illness</p>	 <p>29 out of every 1000 children</p> <p>This may include a temperature or runny nose.</p>
<p>Lower respiratory tract illnesses</p>	 <p>15 out of every 1000 children</p> <p>This may include a cough or chest infection.</p>
<p>Swallowing difficulties</p>	 <p>15 out of every 1000 children</p> <p>This can include increased dribbling or trouble swallowing saliva and liquids.</p>
<p>Urinary incontinence</p>	 <p>15 out of every 1000 children</p> <p>Children who are toilet trained may have urgency to go to the toilet more often or wet themselves.</p>

Severe or life-threatening complications

The procedure carries a very small risk of serious complications that can be life-threatening. Although very rare, BoNT-A can potentially spread to other parts of the body and cause more severe and widespread problems such as difficulties with swallowing and breathing that may increase the risk of pneumonia and death. Seizures in children following injections have been reported but it is not clear if these are linked to BoNT-A itself or not. These events are rare. Please talk with your child’s healthcare team if you would like to discuss any aspect of your child’s planned treatment.

Terms you may hear

Botox® or Dysport®: the trade names for the product botulinum toxin A.

Clinic staff: this may include clerical staff, doctors, nurses, therapists and therapy assistants.

Neurological muscle stiffness: a term used to describe overly stiff or tight muscles caused by disrupted communication among the brain, spinal cord and peripheral nerves.

Spasticity and dystonia: these are words used to describe the stiffness and movement of muscles.

Ultrasound: this device looks at live images of muscles to help the doctor direct the needle into the correct muscle.

Procedure: this refers to the time when both the sedation is given and injections are being done

Sedation: refers to medications (nitrous oxide gas, midazolam and general anaesthetic) that can be offered to children to make the BoNT-A injections less stressful and uncomfortable.