



# A Patient Guide

Information for people who have been prescribed  
botulinum toxin B (NeuroBloc®) for cervical dystonia

## Understanding Cervical Dystonia and Your NeuroBloc® Treatment



This guide describes some of the important facts about Neurobloc that you need to be aware of, however, it does not replace the advice given to you by a healthcare professional. Further very important information about Neurobloc including special warnings and side effects are included in the patient information leaflet which is supplied in each package of Neurobloc. Please remember to ask for the package leaflet if you have not received it and read it very carefully.

# Understanding Cervical Dystonia and NeuroBloc® – How Can This Patient Guide Help You?

This Guide provides information on cervical dystonia and NeuroBloc® (Botulinum Toxin Type B) to help you to understand the condition and the treatment you have been prescribed. In addition, you should also read the NeuroBloc® Patient Information Leaflet, which your doctor will provide to you. The Guide will review cervical dystonia, its treatment, in particular NeuroBloc®, and explain what living with this condition and receiving this treatment will mean for you.

It is important for you to establish a good relationship with the doctors and nurses treating you. All patients are unique and will respond differently to treatment; a good relationship will help you to understand what to expect from the condition in the future.

Together, you should set realistic treatment goals to which you are both committed, to benefit you in living and coping with your cervical dystonia.

Further support: contact with other people suffering with cervical dystonia can also be helpful, either by email or telephone or even by meeting up. The European Dystonia Federation can put you in touch with other cervical dystonia patients ([www.dystonia-europe.org](http://www.dystonia-europe.org)).

If you have any further questions please discuss these with your doctor or nurse or visit [www.neurobloc.com](http://www.neurobloc.com) which also includes a patient information section.

We hope that you will find this guide helpful.

# What is cervical dystonia?

Dystonias are neurological movement disorders affecting different parts of the body, and cause involuntary muscle contractions. A focal dystonia affects just one part of the body.

Cervical dystonia (also referred to as CD or spasmodic torticollis) is the most common focal dystonia. It affects thousands of people per year, about 40,000 in the UK alone and mainly affects nerves supplying your neck and/or shoulder muscles resulting in twisting and repetitive movements. This causes the muscles to be held in abnormal positions that are typically quite painful and may be associated with some tremor.

There are several cervical dystonia types depending on which muscles are involved; your doctor will be able to help you to identify which type you have.

**Torticollis** is the most common form where both head and neck twist, and neck turning may result in the chin pointing to one shoulder



**Anterocollis** results in the chin being pulled down towards the chest

**Laterocollis** is where the head is pulled to one side and down to the shoulder



**Retrocollis** is where the head tilts backwards towards the spine

## Who does cervical dystonia affect and how will it affect you?

Cervical dystonia usually occurs in people over the age of 40 years and is more common in women than in men. Symptoms vary from mild to severe, often associated with pain and/or tremor. These may remain the same, gradually worsen with time, or progress for a few years and then not become any worse. Some 20% of people may even have brief periods without symptoms but in most cases they eventually return. People are affected differently and it is not possible to know, when you are first diagnosed, how it will affect you.

## What symptoms can you expect with cervical dystonia?

The onset of cervical dystonia is typically gradual and marked by increasing spasms of the head and/or neck muscles leading to abnormal head and neck positions. In addition, you may experience:

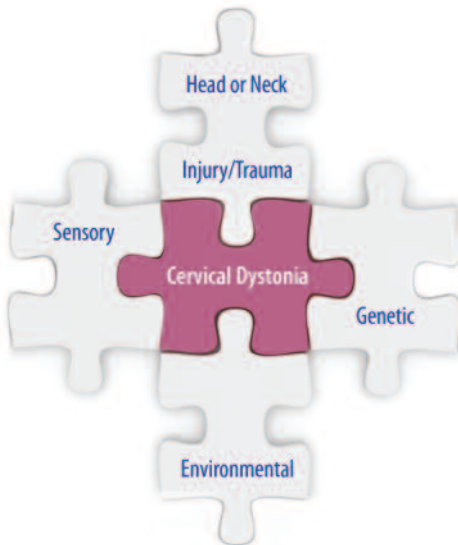
- Limitation of your head and neck movements, making it difficult for you to look over your shoulder while driving or during other activities, and perform simple tasks such as dressing, looking down at a book or computer screen
- Symptoms tend to worsen after stress
- Symptoms generally improve through relaxation or sleep

*You may suffer some or all of these but the severity will vary in different individuals.*

## What causes cervical dystonia?

The exact cause of cervical dystonia is still unclear. Normally the brain sends chemical messages to keep muscle movements smooth and controlled; one of these messengers is acetylcholine. In cervical dystonia it is thought that too much acetylcholine may be produced leading to tense and overactive muscles. Some patients with cervical dystonia do have a history of head or neck injury in their past, but whether this is connected to their dystonia is not yet clear and needs further investigation. It is likely that, as with many diseases, genetic and environmental factors combine to cause the condition.

### *Possible causes of cervical dystonia*



## How is cervical dystonia diagnosed?

The symptoms of cervical dystonia may be quite non specific and intermittent for months or even years, making a diagnosis difficult e.g. only occasional involuntary head rotations. However, the diagnosis, when finally made by your GP or neurologist, will generally be based on some or all of the following:

### ***Your symptoms – these may include:***

- problems with neck/shoulder pain +/- tremor
- abnormal head and/or neck movements
- your difficulties with normal daily tasks

### ***Findings on examination – these include:***

- noticeable thickening of some/all of the affected muscles with some limited movements
- abnormal head/neck positions +/- tremor

*There are no specific tests used to confirm this diagnosis; laboratory tests and imaging scans are usually normal and therefore do not help to diagnose cervical dystonia.*

## How will cervical dystonia affect my life?

This condition affects individuals differently and varies in severity, so it is not possible to know what you or your doctor can expect at the time of diagnosis. Only with time will it become more obvious how you are affected. You should be aware that some daily routine tasks may become more difficult e.g. driving and writing. Again, it will depend how your condition progresses and how well you respond to treatment. If you have difficulty with some daily tasks, physiotherapy and other complementary therapies may help you to achieve relaxation and symptom relief. Again, it is important to work closely with your doctor to ensure that you receive the correct support to help you to cope with your condition.

# Is there a cure for cervical dystonia?

While there is no known cure, cervical dystonia symptoms can be controlled by using oral medications, complementary therapies and/or botulinum toxin injection therapy.

*NB Some individuals with cervical dystonia report that they can find certain positions or 'sensory tricks' that improve their symptoms e.g. temporary head position correction by touching your face, neck or head with your hand or an object, such as a pencil or eyeglasses.*

## How can cervical dystonia be treated?

Treatments are aimed at reducing your symptoms to help you to live your life as normally as possible. In general there are various different approaches to treatment: oral medicines, complementary therapy, toxin therapy and surgery. Your doctor will discuss these with you and advise on which of these is suitable for you.

### ***Oral medications:***

- These include drugs such as anticholinergics e.g. trihexyphenidyl, benzodiazepines e.g. diazepam, and GABA-agonists e.g. baclofen

### ***Complementary (non-medical) care - useful at any time:***

- Physiotherapy can help to improve posture and by working different muscle groups, can help you to increase your movement range
- Supportive therapy and counselling may also benefit, to assist you with any feelings of reduced self-esteem, depression and social isolation which are common feelings for cervical dystonia sufferers





### ***Botulinum toxin therapy:***

Botulinum toxin injections are a widely used treatment for cervical dystonia and can provide patients with improvements in their symptoms.

#### *What are botulinum toxins?*

Botulinum toxins are proteins produced naturally by the bacterium *Clostridium botulinum*. Very small doses of botulinum toxins injected into the overactive muscles help to relax them and provide a usually well tolerated and often effective treatment for cervical dystonia when used under careful medical supervision.

#### *Do all botulinum toxins have the same effect?*

There are several types of botulinum toxins approved for use in cervical dystonia, each with a slightly different make-up and each works slightly differently, although all produce similar effects on the nerves and muscles. Your doctor will choose the type most suitable for you.



### ***Surgery:***

- This is considered only when patients are no longer responsive to other treatments. However, it is not suitable for all patients and is generally regarded as a last line treatment

# Botulinum therapy with NeuroBloc®

## What is NeuroBloc®?

NeuroBloc® is a purified formulation of botulinum toxin type B, produced by *Clostridium botulinum* bacteria. Botulinum toxins are the most commonly used treatment for cervical dystonia and have been discussed earlier.

NeuroBloc® is a type B botulinum toxin and is marketed by Eisai within countries of the European Union.

## How does NeuroBloc® work?



When injected directly into a muscle, NeuroBloc®, like other botulinum toxins, inactivates a protein that normally triggers the release of acetylcholine, a chemical messenger involved in muscle contraction. By preventing acetylcholine release, NeuroBloc® can reduce or prevent muscle contraction and spasm, causing muscle relaxation and so help to relieve your symptoms.

# Is NeuroBloc® suitable for me?

***You should not receive treatment with NeuroBloc® if any of the following apply to you:***

- you are allergic to any of the ingredients in this medicine
- if you suffer from any nerve or muscle disease, especially one causing muscle weakness
- if you are pregnant or breast-feeding

***Take special care with NeuroBloc® and tell your doctor:***

- if you suffer with a bleeding disorder such as haemophilia or are receiving medication such as warfarin, to prevent your blood clotting
- if you have lung problems
- if you have any difficulty swallowing before or after your NeuroBloc® injection. Rarely, severe swallowing problems can result in breathing food or liquids into your lungs and cause pneumonia which might be fatal

If any of these apply to you, please tell your doctor.

*NeuroBloc® is not approved for use in children.*

*You should not normally be given NeuroBloc® if you are under 18 years old.*

## ***Taking other medicines***

Please tell your doctor if you are taking antibiotics for an infection. If you are going to have an operation, please tell your doctor if you have been given NeuroBloc® as it can interfere with medicines you may be given before a general anaesthetic.

Also inform your doctor or pharmacist if you are taking or have recently taken any other medicines, even those not prescribed.

## How will you receive NeuroBloc® ?

NeuroBloc® is a ready mixed solution that will be administered by your doctor or a nurse using a small needle directly into the muscles affected by your cervical dystonia. Your doctor will decide how much NeuroBloc® to give you. The dose will usually be 10,000 units but it can be higher or lower, depending on your doctor's decision and your response to any previous injections of NeuroBloc®. Smaller muscles may require 1-2 injection sites per muscle, while larger ones may require up to 3-4 to ensure that the botulinum toxin reaches all of the parts of the muscle that it needs to. Your doctor may use an electromyogram (EMG) machine or other device to help target the right spot for the injection. Further dosing will depend on the response by the muscles treated.

## What can you expect after a NeuroBloc® injection and how often will you need treatment?

Some people experience some stinging or mild pain at the injection site; this should only be temporary. Any benefits of the injection and symptom improvements will be noticed within 7-14 days and may last for 12-16 weeks, often until the time of the next injection. However, each patient is unique and for some, it may take several injections to achieve maximum benefit. Do not become discouraged if you do not experience major improvements immediately, your doctor will work with you to try to achieve the best results for you.

## Will you experience any side effects or adverse reactions with NeuroBloc®?

As with any medicine, NeuroBloc® can cause side effects, although not everybody will experience them. Side effects with NeuroBloc® are generally mild or moderate, temporary, self-resolving, and more common with higher doses.

Effects may be seen in other areas than where you have received the injection and may occur days to weeks after injection. You may find that your mouth feels dry and/or that swallowing becomes difficult or you experience a shortness of breath. In rare cases, difficulty in swallowing may be severe and choking is possible. If you develop new or worsening swallowing difficulty, choking or breathing problems seek medical help immediately.

You may also notice one or more of the following effects after injection:

***Very common reported side effects*** (likely to occur in more than 1 in 10 patients)

- Dry mouth
- Difficulty swallowing
- Headache

***Common reported side effects*** (likely to occur in fewer than 1 in 10 patients)

- weakness, pain or muscle stiffness around your body
- neck pain
- indigestion
- changes in the taste of your food and drink
- changes in the sound of your voice
- blurred vision
- drooping of the upper eyelid
- vomiting
- constipation
- flu-like symptoms
- loss of strength or energy

It is also possible that torticollis (turning of your head which you cannot control) could become worse after you have had your injection.

If any of the side effects get serious or if you notice any side effects not listed in this Guide, please tell your doctor or pharmacist.

NB. Your doctor should be aware of any previous treatments you have received for cervical dystonia, as well as any other medications that you are taking.

*For the full list of side effects reported with NeuroBloc® and warnings and precautions for its use, please ask your doctor for the patient information leaflet which accompanies the medication.*

## Important

Following NeuroBloc® treatment, you should seek medical attention immediately if you experience respiratory difficulties, choking or any new worsening swallowing difficulties.

## How will your NeuroBloc® treatment continue?

Since every patient is different, your doctor will work with you over time to adjust the dose of NeuroBloc® to ensure that you receive maximum relief of your cervical dystonia symptoms, while keeping side effects as minimal as possible.

## Treatment Goals

As part of your toxin therapy, it is important that you discuss treatment goals with your doctor so that treatment can be tailored to your individual needs e.g. the daily lifestyle that you wish to live, as far as your condition allows.

## Additional Support

As with any medical condition, the best people to discuss any problems or issues with are the doctors and nurses treating you. There is also support and further information available from the following:

### THE EUROPEAN DYSTONIA FEDERATION (EDF)

The EDF provides information and support to those suffering with all types of dystonia and can offer you and your family practical ways to cope with your condition. The EDF includes a number of member societies in different countries, whom you can contact to put you in touch with others suffering with this condition.

Please visit [www.dystonia-europe.org](http://www.dystonia-europe.org).



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