

Information booklet for patients with cervical dystonia receiving Dysport® (*Clostridium botulinum* type A toxin-haemagglutinin complex)



This booklet was commissioned by Ipsen Ltd, and is intended for adult patients prescribed Dysport® for the symptomatic treatment of spasmodic torticollis (cervical dystonia).

If you get any side effects, talk to your healthcare professional. This includes any possible side effects not listed in this booklet. You can also report side effects directly via the Yellow Card Scheme at <https://yellowcard.mhra.gov.uk/> or search for MHRA Yellow Card in the Google Play or Apple App Store. Side effects should also be reported to Ipsen via email at pharmacovigilance.uk-ie@ipsen.com or phone on 01753 627777. By reporting side effects, you can help provide more information on the safety of this medicine.

This booklet aims to provide you with information about Dysport® treatment and what to expect during the treatment process. It may also help you to talk to your healthcare professional about why you are having treatment and what you may experience.

This booklet does not replace the Patient Information Leaflet provided with this medicine. Please ask your healthcare professional for the Patient Information Leaflet for further information on this medicine. To access an online version of the Patient Information Leaflet, please visit:

<https://www.medicines.org.uk/emc/product/964/pil>

What is cervical dystonia?

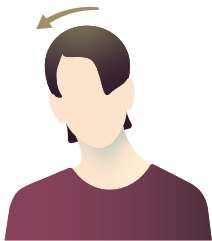
Spasmodic torticollis (also known as cervical dystonia) is a condition that causes neck muscles to tighten or spasm, making the head turn, pull in one direction, or causes shakes (known as tremors). The involuntary contractions may be continuous or occur as spasms. This abnormal movement can sometimes make it difficult to stop your head from turning to the side, tipping forward or backwards. In some people, symptoms may seem to disappear without treatment, but recurrence is common.

Some factors (such as stress) can make your condition worse.

Cervical dystonia can vary in severity and take many forms. Below are some of the most common:

- head tilting to the side (known as laterocollis)
- head turning to the side (known as torticollis)
- head tilting forwards (known as anterocollis)
- head tilting backwards (known as retrocollis)

Forms of cervical dystonia¹



Laterocollis



Torticollis



Anterocollis



Retrocollis



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It is possible to have a combination of the different forms, depending on the muscles that are affected. As cervical dystonia can affect individuals in different ways, the treatment plan is unique for each patient. It is important to discuss your treatment plan in detail with your healthcare professional and agree on treatment goals.



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Possible causes of cervical dystonia

There is no one known cause of cervical dystonia, but there may be a genetic component. Sometimes, cervical dystonia may develop after a head, neck, or shoulder injury.

Your treatment plan

Before any treatment is given, your healthcare professional will discuss your treatment goals with you; this is very important as it will help them recommend the most appropriate treatment plan.

For example, your treatment goals may be to reduce pain as a result of your condition, reduce abnormal movements or neck twisting, improve your movement or make daily activities easier. The goals set may change depending on how your current treatment is working.

Therefore, it is important to openly discuss your progress during the appointments with your treating healthcare professional.

Your treatment plan may include using medicines to help with your symptoms, and may also include non-medical treatments, for example physiotherapy and/or complementary therapies.



If you have any questions about your treatment, please always discuss these with your treating healthcare professional.

Your treatment

Dysport® injections have been prescribed as part of your treatment plan. These injections can help control the symptoms caused by cervical dystonia.

How does this medicine work?

This injection contains the active substance botulinum neurotoxin type A, which is produced by the bacteria *Clostridium botulinum*. It works by stopping your muscles contracting, which helps to reduce abnormal muscle contractions known as spasms.²

Other treatments, such as physiotherapy, can be used alongside this medicine to help with your movement and balance. Your healthcare professional will discuss these options with you.

How will this medicine help you?

Your healthcare professional thinks these injections can help improve muscle function by potentially reducing the pain or abnormal movement in your neck, therefore improving the position of your head and neck.

By reducing your muscle spasms/stiffness, it can also help improve the position of your head and reduce any pain you may have. This may help you achieve the treatment goals you had set with your healthcare professional.

What to expect from these injections²

Because this injection works by stopping your muscles contracting, it may help reduce spasms and stiffness. It usually takes 1 week for you to start feeling symptom relief. The effects of the injections are temporary and treatment will need to be repeated approximately every 16 weeks. or as needed, but not more frequently than every 12 weeks.

Some other medicines or conditions may affect your treatment with Dysport®. Before you start this treatment, your treating healthcare professional will ask you a number of questions about other medicines you are taking. It is important to mention to your healthcare professional if:²

- you are taking any other medicines with or without prescription, including antibiotics (such as gentamicin or amikacin) or muscle relaxing drugs
- you have problems swallowing
- you have any history of bronchitis, chest infections or problems with breathing
- you have had an allergic reaction to a botulinum toxin injection, human albumin or lactose in the past
- you have other problems or diseases that affect your muscles
- you bleed easily or you are taking any medicines that can thin the blood (such as aspirin, clopidogrel, heparin or warfarin)
- you have an infection where the injection will be given or the area is swollen
- your muscles at the proposed site of injection are weak or show signs of wasting
- you are pregnant or breast-feeding, think you may be pregnant or are planning to have a baby. Please ask your healthcare professional for advice before taking this medicine. Dysport® is not recommended during pregnancy, unless clearly necessary, or during breast feeding, and may affect fertility
- you have a urinary tract infection. Do not use Dysport® if you have a urinary tract infection at the time of receiving treatment for leakage of urine

You may also show your healthcare professional the medicines you are taking so he/she can check for you.

How will this medicine be given?

Dysport® is given as an injection by a qualified and trained healthcare professional into the affected muscles in your neck. Your treating healthcare professional will decide on the required dose, which muscles should be injected and the treatment schedule based on your condition and agreed goals.²

Sometimes your healthcare professional may use a technique called electromyography (which registers the activity of muscles) or ultrasound (which gives a picture of the muscles) to help target injection sites.

- Anaesthetic cream or cold spray may be used at the injection site to dull the needle prick for each muscle that is affected
- For those who are anxious of needles or who require more than one treatment cycle, a light sedative may be given to relieve anxiety



How long does it take for the injection to start working?²

You may see improvement in your symptoms, including muscle stiffness and spasms, within 1 week after injection.



How often will injections be given?²

Your healthcare professional will repeat the treatment approximately every 16 weeks, or as needed, but not more frequently than every 12 weeks.

If you experience any muscle weakness or problems with your vision following an injection, do not drive or use any machines and speak to your healthcare professional.²

If you have any questions about your treatment, please speak to your healthcare professional.

What are the possible side effects of Dysport®?²



Like all medicines, Dysport® may cause side effects, although not everyone will experience them.

As this medicine is injected into a muscle causing spasms, you may see reactions around the injected area. In very rare cases, this medicine may cause side effects which appear away from the injection site, related to the spread of the toxin effect and botulism. These symptoms have been reported from hours up to several weeks after the injection.



Seek urgent medical help if you experience the following after receiving this injection:

- double vision, blurred vision and/or drooping eyelids, excessive muscle weakness, difficulty swallowing, coughing and choking when swallowing, or difficulty speaking or breathing. These symptoms may appear hours to weeks after your injection
- you develop difficulty in your breathing, with or without swelling of the face, lips, tongue and/or throat, redness of the skin or an itchy lumpy rash (urticaria). This means you may be having an allergic reaction to the injection

Please see below some side effects that were seen in clinical trials of patients who received Dysport® injections:

Treatment of any condition (all patients):

Common: may affect up to 1 in 10 people
Bruising, or pain around the site where the injection was given
Brief period of generalised weakness
Tiredness
Flu-like symptoms
Uncommon: may affect up to 1 in 100 people
Itching
Rare: may affect up to 1 in 1,000 people
Skin rashes
Sudden severe pain and weakness in the shoulder and/or arm

Treatment of cervical dystonia:

Very common: may affect more than 1 in 10 people
Muscle weakness
Difficulty in swallowing. This side effect may be expected to resolve within 2 to 4 weeks
Dry mouth

Common: may affect up to 1 in 10 people

Headache

Dizziness

Blurred vision or other problems in seeing clearly

Weakness of face muscles

Stiff muscles

Shortness of breath

A change to the tone of the voice

Neck pain, muscle pain, pain in the hands and fingers

Uncommon: may affect up to 1 in 100 people

Loss of muscle tissue

Jaw problems

Drooping of the upper eyelid

Double vision

Nausea

Rare: may affect up to 1 in 1,000 people

Lung inflammation caused by accidentally breathing in food, drink, saliva or vomit (aspiration pneumonia)

If you experience any side effects, talk to a healthcare professional straight away. This includes any possible side effects not listed in this booklet.



What should you do if you are given more Dysport® than you need?

If you are given more Dysport® than you need, muscles other than the ones that were injected may begin to feel weak. This may not happen straight away. If this does happen, speak to your healthcare professional immediately. Seek urgent medical help if you have difficulty breathing, swallowing or speaking.



What should you do if you forget an injection of Dysport®?

Nothing will happen if an injection is missed other than some of the spasm or muscle stiffness may return. Tell your healthcare professional and they will decide when the next injection is needed.



What should you do if you see a different healthcare professional?

If you visit a different healthcare professional for any reason regarding your condition it is important to tell them that you are receiving Dysport® injections.

Talking to your healthcare professional



Talking to your treating healthcare professional about your treatment with Dysport® and its possible side effects can help to prepare you for what to expect.

Some people may find visiting hospitals or having injections frightening. It may be helpful to ask your healthcare professional what your treatment process will involve and ask them to explain this to you.

You may not see the effects of treatment immediately after injection, or your benefits may wear off before your next appointment. Therefore you may require repeat injections to relieve your symptoms. Always discuss with your healthcare professional about your treatment progress.

Should you feel that you are not responding to treatment following the injections or the effects wear off quickly before your next appointment, please report this to your healthcare professional at your next appointment.

Stress can sometimes make your condition worse, therefore it will be helpful to discuss with your healthcare professional about any issues which may cause the stress or any alternative therapies which may be available. Do not try therapies without speaking to your healthcare professional first.

Your healthcare professional can also advise on any coping strategies or exercises to help with your condition or your rehabilitation.

Sometimes it may not be possible to stop the spasms in your neck completely. If you feel that your condition is not improving, speak to your healthcare professional about this.

Physiotherapy exercises to try at home

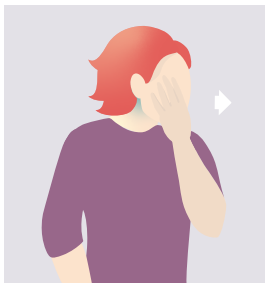
Below are some physiotherapy exercises that can be used to help improve movement in the muscles of your neck. These can be done at home in between your hospital appointments. These exercises are not to replace the ones provided at the hospital. Please speak to your healthcare professional if you have any questions.

Gentle neck exercises (1):



1. Sit with your head facing forward
2. Reach over with your arm to your opposite ear. Bend your neck to the side, attempting to bring your ear close to your shoulder

Gentle neck exercises (2):



1. Sit upright
2. Turn your head to the side, at the same time lowering your opposite shoulder
3. Try and maximise how much you stretch by tilting, extending and/or rotating your neck

Gentle neck exercises (3):



1. Position yourself with your head facing forwards and in a central position
2. Bend your neck forwards to face downwards, hold for 3 seconds, then bring your head back to a central position
3. Bend your neck backwards to face upwards, hold for 3 seconds, then bring your head back to a central position

Additional support

If you would like additional information and support on cervical dystonia, ask your healthcare professional about local support groups. Additional sources of support are detailed below:

The Dystonia Society (www.dystonia.org.uk)

The Dystonia Society is a national charity providing support, advocacy and information for anyone affected by dystonia.

NHS 111 (111.nhs.uk)

You can call 111 (free from landlines and mobile phones) or visit 111.nhs.uk when you need urgent medical help but it's not a 999 emergency. NHS 111 is available 24 hours a day, 7 days a week.

For further information please contact your healthcare professional.

Treatment details

Contact details

You can ask the healthcare professional who is managing your cervical dystonia to help you fill in this page.

Your treating healthcare professional is:	
Contact number:	

Appointments schedule

Time	Date	Location

References

1. Jost WH and Tatu L. Selection of Muscles for Botulinum Toxin Injections in Cervical Dystonia. Movement Disorders Clinical Practice 2015;2:224–226.

2. Dysport® Patient Information Leaflet, Ipsen Ltd.
Available at: <https://www.medicines.org.uk/emc/product/964/pil> and <https://www.medicines.org.uk/emc/product/7261/pil>. Accessed August 2026.

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