

Guidance for local use

This factsheet is designed to bring additional context around the neurological condition cervical dystonia for local media outreach around the first published cervical dystonia patient journey map (CDPJM). Developed in collaboration with Dystonia Europe, the CDPJM was recently published in the *Orphanet Journal of Rare Disease* and supported by a template press release.

Please use this factsheet to support the CDPJM publication milestone, for general media disease education, and to highlight Ipsen's commitment more broadly to improving outcomes for people living with cervical dystonia.

Please note that this asset requires local adaption and approval for any external media distribution. For further information or support, please contact: gwenan.white@ipsen.com; oleks.gorbenko@ipsen.com

Media Factsheet: Understanding cervical dystonia

What is cervical dystonia?

- Cervical dystonia (also known as spasmodic torticollis) is a neurological movement disorder that causes involuntary muscle contractions, leading to twisting and repetitive movements or abnormal postures.¹
- It may be restricted to the neck only or accompanied by dystonia in other body parts, such as the hands or face.^{1,2}

What causes cervical dystonia?

- The cause of cervical dystonia is often unknown – however, evidence suggests that both genetic and environmental factors may play important roles.³
 - Recent research suggests ~15% of patients with cervical dystonia have a family member affected with dystonia.⁴

Is it considered a rare disease and what is the prevalence?

- Cervical dystonia is rare, affecting 57 to 280 people per million.⁵
- It can occur at any age, although symptoms generally appear in middle age, often beginning slowly and usually reaching a plateau over a few months or years.⁶

What are the main symptoms?

- Cervical dystonia is characterized by involuntary muscle contractions in the neck that cause abnormal postures of the neck and head, such as twisting and repetitive movements.¹
- For some people, these abnormal contractions may be sustained or continuous; in others, they may be present as spasms that can resemble tremor.⁷
- The severity of cervical dystonia can vary, but the disorder can cause significant pain and discomfort localized to the shoulders and/or the back of the head.²

What is the impact on people's lives?

- Cervical dystonia can significantly affect quality of life and activities of daily living, ranging from a minor inconvenience to a significant disruption of normal life including:⁷⁻¹⁰
 - Ability to work
 - Ability to have social interactions
 - Ability to drive confidently
 - Sleep disturbance
 - Ability to perform daily tasks

Management approaches

- There is currently no cure for cervical dystonia, and most therapies are designed to alleviate symptoms, including spasms, pain and disturbed postures.²

- Multiple treatment options exist including regular botulinum toxin injections, oral medications and, in some cases, surgery. Botulinum toxins act by temporarily weakening dystonic muscles to decrease strength of the contractions.^{2,3}
- Oral medications for pain or head tremor and deep brain stimulation are available for people not responding positively to botulinum toxin.²
- A cervical dystonia patient journey map (CDPJM) was recently published, describing the patient experience from pre-diagnosis through to long-term treatment.¹¹
 - Patients highlighted a “rollercoaster” of relief associated with the (standard first-line) botulinum toxin treatment, with symptoms returning towards the end of an injection cycle.
 - The map also underlined the need for a multidisciplinary management plan to ensure that people living with cervical dystonia can access complementary services such as physiotherapy and psychosocial support.

References:

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