

Cervical Dystonia

Condition: Cervical Dystonia (CD) is a condition affecting head or neck muscles caused by localized abnormal muscle activity.

Background: CD may cause one or more of the following symptoms: abnormal neck or head positions or postures, involuntary movements, tremor, muscle spasms or pain. Movements in CD often appear twisting and can also be tremulous. The most frequent cause of CD is idiopathic adult-onset focal dystonia (idiopathic, meaning, no specific cause for dystonia is found). Focal dystonia is a type of dystonia which affects a single body region Ex. cervical (i.e., neck) or cranial (head). While there are many theories as to what causes idiopathic focal dystonia (including CD), one commonly accepted theory is that it is due, at least in part, to alterations in the brain pathways that regulate sensory-motor control.

Risk Factors: Certain genetic variants have shown increased risk for primary Cervical Dystonia including (GNAL, THAP1, CIZ1, ANO3) and inherited causes like DYT23. CD is slightly more common in females than males. There are other conditions that can lead to secondary or acquired cervical dystonia including: viral encephalitis, Wilson's disease, Parkinson's, anticholinergic and neuroleptic medications, trauma from cervical injuries. This list is not all encompassing and other conditions can lead to the development of Cervical Dystonia.

History and Symptoms: Most patients with idiopathic CD are adults between 40-60 years of age. Patients have often had symptoms for several years before a diagnosis of CD is made. Symptoms vary, but most patients with CD will report movements that are either" twisting or tremulous, constant or intermittent or combinations of both. Patients also may report their symptoms may get worse with fatigue, stress, excitement, or certain activities. Some patients report that their symptoms improve with sensory tricks such as touching the cheek or back of the head.

Physical Exam: Examination head and neck region may reveal limited movement and or resistance to stretching a muscle in the opposite direction to a posture. Limited motion in the neck/head/chin (tilt, rotation, forward bending or backward bending), tremor, asymmetry of the face or shoulder, and occasionally weakness. Palpation of muscles may help to identify increased or decreased muscle bulk or pain. Some patients also report numbness, or tingling.

Diagnostic Process: CD is a "clinical diagnosis". This means that there is no one test or tests that can be ordered to prove that CD is present. Your doctor may request one or more studies including blood tests, X-rays, MRI or muscle and nerve tests to help eliminate other conditions that may mimic CD. Additionally, genetic testing can be considered for the above-mentioned genetic variants.

Treatment: Botulinum toxin (BoNT) injections are approved by the FDA and are the treatment of choice for nearly all patients with CD. Medications by mouth may be recommended for patients who have incomplete benefit with BoNT injections. Lastly surgery (deep brain stimulation) may be recommended for patients who with severe CD that does not respond to other treatments.

Rehab Management: **Prior to and or following** injection of BoNT your doctor may recommend a rehabilitation program including physical therapy. Physical Medicine and Rehabilitation (PM&R) physicians, also known as physiatrists, are physicians who receive extensive training in neurological and musculoskeletal conditions, anatomy, procedures and in prescribing rehabilitation programs for these conditions. This training provides PM&R physicians with unique skills in treating patients with CD. PMR physicians have training in techniques to increase

the efficacy and safety of BoNT injections including the use of electromyography (EMG) or ultrasound (US) to guide the injections. US, often in combination with EMG, is preferred by many PMR physicians to guide injections because US allow the muscle targets and the needle to be visualized at all times. Your physician may prescribe PT prior to and after BoNT injections. While the evidence for the efficacy of PT for CD, by itself, is limited, PT after BoNT injections may improve motion and provide symptomatic relief. The use of devices such as soft or hard collars is often limited to specific times of the day, for example, when watching TV. Soft cervical collars have not been shown to be helpful in patients with Cervical Dystonia.

Other Resources for Patients and Families: The Dystonia Medical Research Foundation provides additional education and support for patients and families.

Frequently Asked Questions

What is PM&R?

Physical medicine and rehabilitation (PM&R), also known as physiatry, is a primary medical specialty that aims to enhance and restore functional ability and improve quality of life to those with injuries, physical impairments or disabilities affecting the brain, spinal cord, nerves, bones, joints, ligaments, muscles and tendons. PM&R physicians, known as physiatrists, evaluate and treat the whole body, maximize patients' independence in their daily life and are experts in designing comprehensive, patient-centered treatment plans to empower patients to achieve their goals. By taking the whole body into account, they can accurately pin-point problems, decrease pain, assist in recovery from devastating injuries and maximize overall outcomes and performance with non-surgical and peri-surgical options. To learn more, visit www.aapmr.org/aboutpmr.

What makes PM&R physicians unique?

PM&R physicians' training focuses not just on treating medical conditions, but on enhancing the patient's performance and quality of life in the context of those medical conditions. They focus not only on one part of the body, but instead on the development of a comprehensive program for putting the pieces of a person's life back together – medically, socially, emotionally and vocationally – after injury or disease. PM&R physicians make and manage medical diagnoses, design a treatment plan and prescribe the therapies that physical therapists or other allied therapists perform or that are carried out by the patients themselves. By providing an appropriate treatment plan, PM&R physicians help patients stay as active as possible at any age. Their broad medical expertise allows them to treat disabling conditions throughout a person's lifetime.

Why see a PM&R physician?

A PM&R physician will thoroughly assess your condition, needs, and expectations and rule out any serious medical illnesses to develop a treatment plan. By understanding your condition and goals, you and your PM&R physician can develop a treatment plan suited to your unique needs.

How do I find a PM&R physician near me?

Visit www.aapmr.org/findapmrphysician or contact your primary care physician for a referral.