



Dystonia Statistics

Care4Dystonia, Inc.

We've compiled statistics (fast figures) on the following forms of dystonia on this page :

1. Idiopathic dystonia
2. Dopamine-responsive dystonia
3. Writer's cramp
4. Tardive dystonia
5. Cervical dystonia (torticollis)
6. Spasmodic dysphonia
7. Blepharospasm

Frequency of Idiopathic Dystonia:

- ▶ **In the US:** The relative frequencies of primary and secondary forms of dystonia are not known.

In the Movement Disorder Center at Columbia Presbyterian Medical Center, the vast majority (ie, 71%) of over 3000 patients with the disorder had primary torsion dystonia; the remaining 29% had secondary etiologies, with tardive dystonia being the leading acquired cause (unpublished data).

In a study from Rochester, Minnesota, the prevalence of generalized primary dystonia was reported to be 3.4 per 100,000 individuals and of focal primary dystonia, 29.5 per 100,000 individuals (Nutt et al, 1988).

- ▶ **Internationally:** In a recent European collaborative study (Epidemiological Study of Dystonia in Europe [ESDE]), the investigators found a crude annual prevalence of 15.2 per 100,000 individuals, the majority having focal dystonia at a rate of 11.7 per 100,000 (ESDE Collaborative Group, 1999).

Race: Childhood- and adolescent-onset primary dystonia has been found to be more common in Jews of Eastern European or Ashkenazi ancestry.

Sex: In a large study of 957 cases of primary dystonia from Europe, segmental and focal dystonias were reported to have significant female predilections, suggesting that patients with focal dystonia should not be treated as a homogenous group and that sex-linked factors may play a role (ESDE Collaborative Group, 1999).

At C4D we believe that there are more than 350,000 people with dystonia in N.A based on increased recognition and awareness.

Frequency of Dopamine-responsive Dystonia DRD

- ▶ **In the US:** Epidemiological studies are not available.
- ▶ **Internationally:** Epidemiological studies are not available, but most cases have been reported from Japan and Southeast Asia. With increasing awareness of this condition, more cases are being reported from other parts of the world.

Frequency of writer's cramp:

- ▶ **In the US:** One study estimated the prevalence rate to be 69 per 100,000; this is thought to be an underestimation because a high percentage of patients never seek medical assistance.
- ▶ **Internationally:** Again, because of the small percentage of affected patients seeking medical attention, accurate prevalence estimates are not available.

Sex: Prevalence is slightly higher in men; the male-to-female ratio is 1.3:1.

Age: Typically, patients present in the third to fifth decades, and women usually present earlier than men.

Frequency of tardive Dystonia:

- ▶ **Internationally:** The prevalence of tardive dystonia is 0.5-21.6% of patients who are treated with neuroleptics. This condition undoubtedly is less common than oral-buccal-lingual tardive dyskinesia. In a survey of 555 psychiatric patients, Yassa et al found a prevalence rate of 34% for oral tardive dyskinesia and only 1.4% for tardive dystonia. Similarly, Friedman and coworkers found a prevalence rate of only 1.5% among 352 hospitalized psychiatric patients. One recent study by Sethi et al (1990) indicated a prevalence rate of 21% for tardive dystonia among veterans institutionalized long-term. However, most of these cases were mild; only 20% were symptomatic.

Mortality/Morbidity: Tardive dystonia causes pain and physical and emotional disability. Disability is moderate to severe in 70% of patients with tardive dystonia.

Frequency: of cervical dystonia (torticollis):

- ▶ **In the US:** Reports of incidence are available primarily from the United States and Canada. Posttraumatic cases account for 10-20% of patients; the others are idiopathic. Consky and Lang (1994) have reviewed several series to determine the relative frequency of torticollis types, with the following conclusions: (1) most cases of torticollis have mixtures of movements; (2) "spasmodic" features presumably dominate and relate to the classic descriptor of head jerks and spasms, hence the term "spasmodic torticollis" (no consensus exists regarding that description; the term "cervical dystonia" is preferred); (3) torticollis with some degree of rotation is the most common individual type; and (4) after torticollis in frequency come laterocollis and then retrocollis, with anterocollis the rarest form.
- ▶ **Internationally:** No data are available except from Canada (see above).

Mortality/Morbidity: These conditions do not usually lead to death, and life span is normal. Morbidity concerns 3 areas that may require additional treatment.

- ▶ Chronic pain due to dystonia or due to strain in attempts to compensate for abnormal postures
- ▶ Cervical spondylosis from chronic abnormal dystonic posture, which can lead to radiculopathies and/or spinal stenosis
- ▶ Social embarrassment or the extreme of social isolation with depression

Race: No racial predominance is reported for torticollis.

Sex: Torticollis is reported twice as often in females as in males.

Age: Onset of idiopathic cervical dystonia typically occurs when patients are aged 30-50 years. Onset of posttraumatic cervical dystonia is within days of injury for the acute form and 3-12 months after injury for the delayed form.

Frequency of Spasmodic Dysphonia:

Early textbooks reported that SD was a relatively rare voice disorder, although recent reports suggest that it is not a rare disorder but rather is one that frequently goes undiagnosed. Most studies show that this disorder affects females more commonly than males, with a female-to-male ratio as high as 8:1.

Reports of the mean age of patients with SD typically indicate a range of 48-50 years; however, the condition may occur as early as the second decade of life in rare exceptions and as late as the ninth decade.

Although a genetic basis has not been established for SD, some patients (12%) report relatives with similar voice problems or other dystonias (Blitzer et al). Abductor SD is rarer than the adductor type (13% of all patients with SD). Patients have prolonged voiceless consonants because of difficulties with voice onset following voiceless sounds such as /h/, /s/, /f/, /p/, /t/, and /k/.

Frequency of Blepharospasm:

- ▶ **In the US:** It is estimated that there are at least 50,000 cases of blepharospasm in the United States, with up to 2000 new cases diagnosed annually. The prevalence of blepharospasm in the general population is approximately 5 in 100,000.

Mortality/Morbidity: At one end of the clinical spectrum, essential blepharospasm is manifested by simple increased blink rate and intermittent eyelid spasms, while at the other end of the spectrum, blepharospasm is a disabling condition with ocular pain and functional blindness. Patients may report that they are disabled to the point where they have stopped watching television, reading, driving, and/or walking. Patients may develop anxiety, avoid social contact, become depressed, become occupationally disabled, and become suicidal.

Sex: A female preponderance of 1.8:1 exists.

Age: The mean age of onset of blepharospasm is 56 years, and two thirds of patients are age 60 years or older.

Source : Stats are from 2000-2002 scientific papers in Neurology and Movement Disorders Journal.