

DMRF CANADA – THE DYSTONIA SURVEY REPORT



**REAL PATIENTS.
REAL ANSWERS.**

The Dystonia Canada Report: Requirements for
Dystonia Patients and their Families in Canada.

SUMMARY OF THE DYSTONIA CANADA SURVEY

- **The focus of the Dystonia Survey:** To provide a comprehensive evaluation of the experiences, fears, feelings and thoughts of Canadians living with dystonia, to help the DMRF Canada develop a long-term strategy for better supporting this patient population in the current environment.
- **About The Survey:**
 - The first of its kind in Canada;
 - Over 600 responses from dystonia patients across Canada;
 - Responses were collected using the following channels: online (email promotion), social media (Twitter and Facebook), in print via the DMRF Canada Fall 2016 Newsletter, via movement disorder clinics across Canada. Surveys were distributed in both official languages;



SUMMARY OF THE DYSTONIA CANADA SURVEY



- **Survey Questions focused on;**
 - Basic participant demographics;
 - Form of dystonia;
 - Neurotoxin Use:
 - History, frequency of use, satisfaction and payment methods;
 - Patient Experience:
 - interests, requests for support, feelings, challenges



REAL RESPONSES

OVERVIEW OF THE DATA

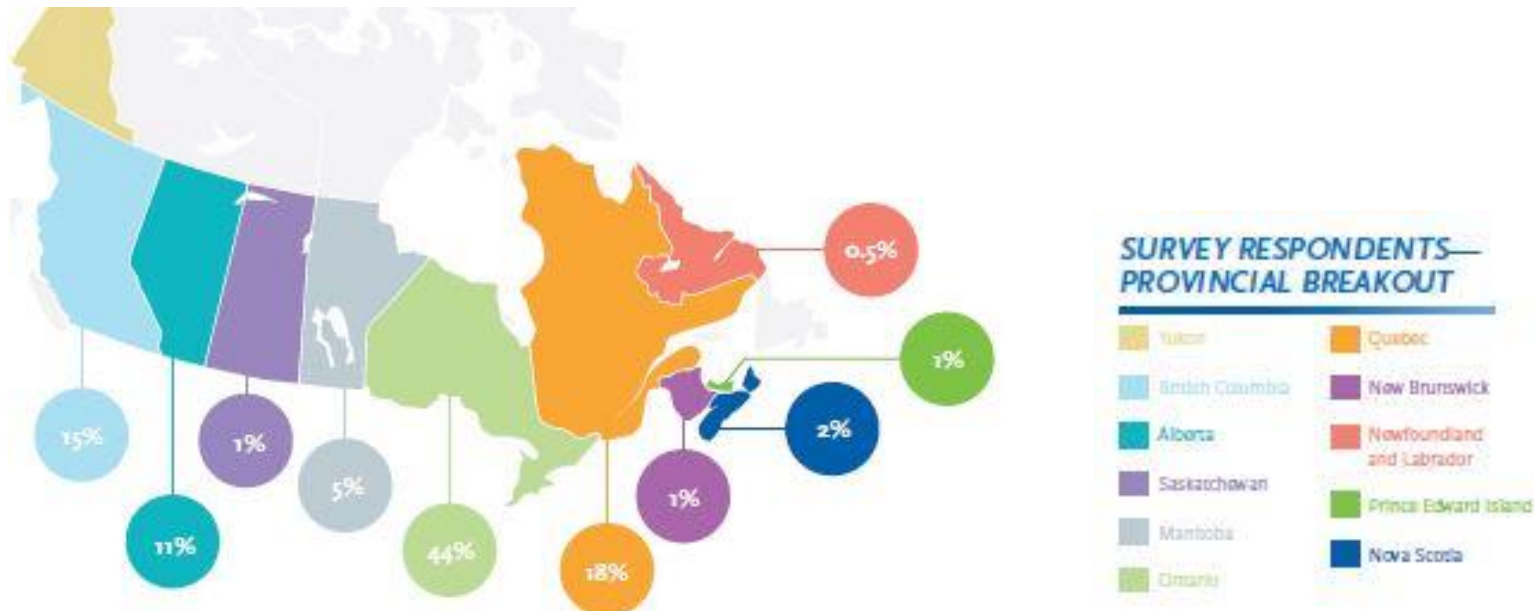
People really suffer from this disease. Thank you for helping to raise awareness for a condition few people even know about.

– Survey Respondent

THE DYSTONIA CANADA REPORT – REAL PATIENTS – SURVEY RESPONDENTS



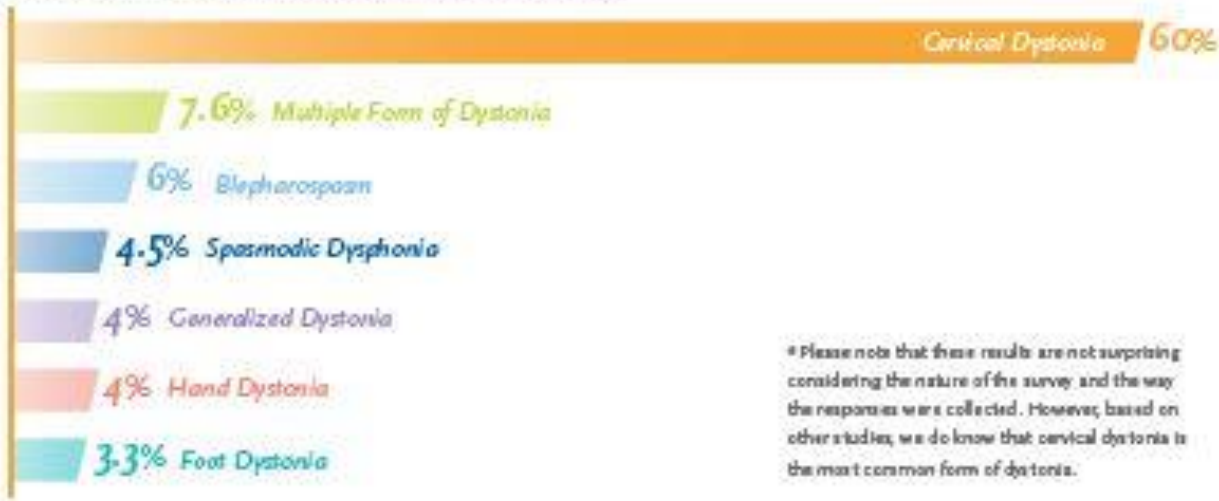
- The Dystonia Canada report – 613 Surveys were included in English and French;
- 79% of respondents were female;
- 41% of respondents were between the age of 41 – 65 and 31% were over the age of 65. Only 9% were under the age of 41;



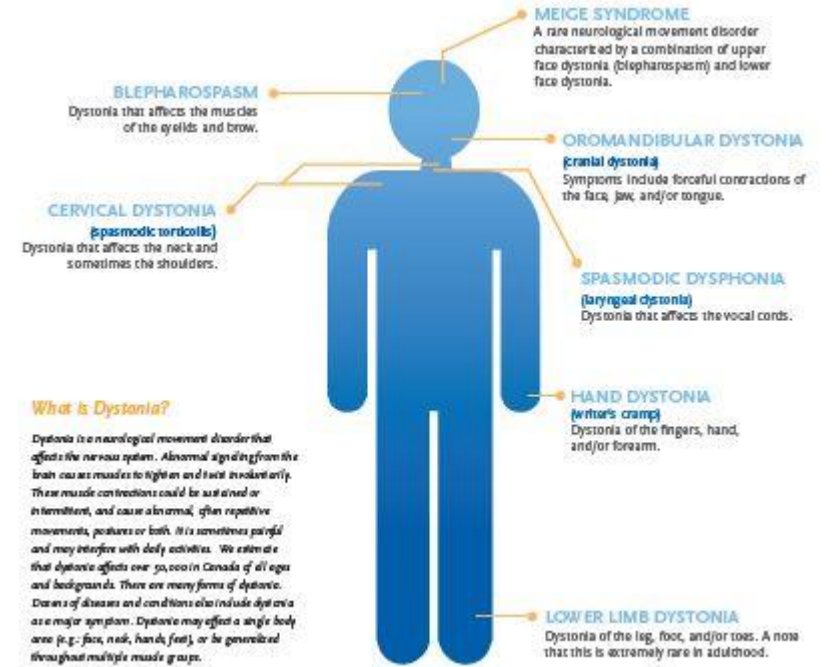
THE DYSTONIA CANADA REPORT – FORMS OF DYSTONIA

Patients Respond: Forms of Dystonia

The majority of survey respondents confirmed that they had cervical dystonia (60% of respondents),* but other forms of dystonia were listed, including:



* Please note that these results are not surprising considering the nature of the survey and the way the responses were collected. However, based on other studies, we do know that cervical dystonia is the most common form of dystonia.



THE DYSTONIA CANADA REPORT – DYSTONIA TREATMENT – THE USE OF NEUROTOXIN



- Trends in Neurotoxin Use:
 - 62% of survey respondents confirmed that they currently receive neurotoxin injections for their dystonia;
 - 89% of patients who have blepharospasm use a neurotoxin;
 - 32% of patients who have generalized dystonia currently use a neurotoxin;
 - Inconsistency in use among provinces – for further investigation

62%

*of survey respondents
confirmed that they currently
receive botulinum neurotoxin
injections for their dystonia.*

THE DYSTONIA CANADA REPORT – DYSTONIA TREATMENT – THE USE OF NEUROTOXIN



- Frequency of neurotoxin injections among patients:
 - 63% receive injections every 12 weeks;
 - 19% receive injects less frequently than every 12 weeks;
 - 18% are being injected more frequently.

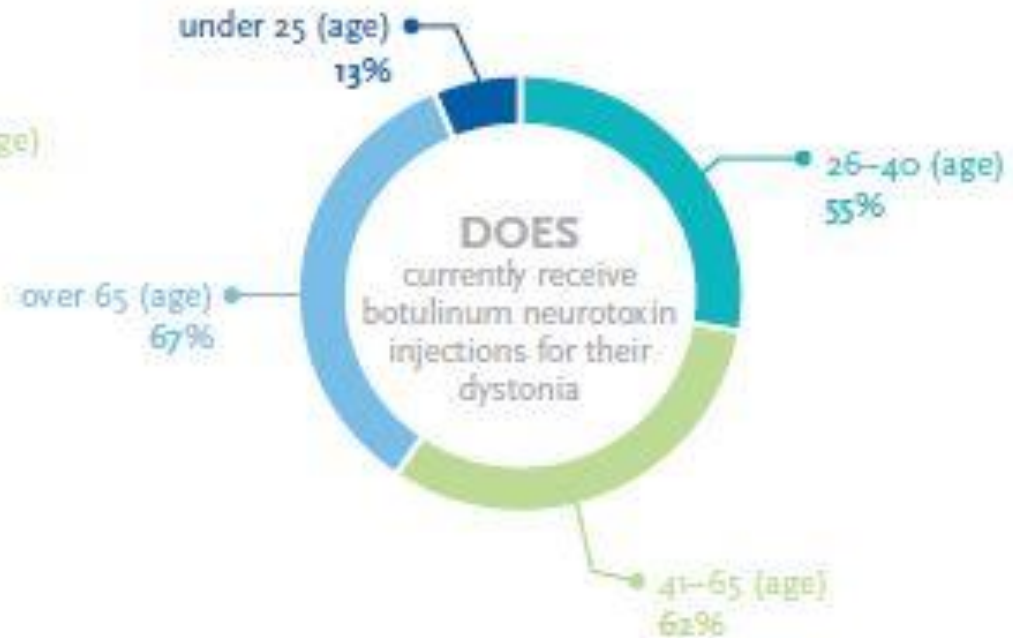


THE DYSTONIA CANADA REPORT – DYSTONIA TREATMENT – NEUROTOXIN USE BY AGE



- A higher percentage of respondents over the age of 41 were users of neurotoxin than those under the age of 41.
 - For individuals under the age of 25 only 12.5% were users of neurotoxin;
 - For individuals between the age of 26 and 40, 55% were users of neurotoxin, which is lower than the overall average of 62%;
 - Finding only clarifies that younger patients have more generalized dystonia and are therefore less likely to receive injections.

THE DYSTONIA CANADA REPORT – DYSTONIA TREATMENT – THE USE OF NEUROTOXIN



THE DYSTONIA CANADA REPORT – HOW IS NEUROTOXIN TREATMENT COVERED



- 86% of those survey respondents who used a neurotoxin had that treatment covered in part or in full;
 - 53% of the 86% had their treatment covered in full;

33%

have private insurance, but it doesn't pay for 100% of coverage.

29%

are 100% covered by their provincial plan

24%

have private insurance that pays 100% of their medication cost

The question we did not ask, but will explore further in the future, is how a person's medical coverage may have impacted their choice to seek out appropriate treatment methods. From the perspective of the DMRF Canada, it is important that all dystonia patients have access to the same coverage for the best treatment for their dystonia.

THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED



Satisfaction with Neurotoxin

- For all individuals who use neurotoxin, **only 13% describe their dystonia as ‘under good control’ on the scheduled day of their injection appointment.** 38% describe it as ‘manageable’ and 24% describe it as troublesome;
- **25%** confirmed; *“my dystonia status seems to be different each time I go for treatment, it may be okay or it may be troublesome”.*

13%
under good control

38%
manageable

24%
troublesome

25%
inconsistent

THE DYSTONIA CANADA REPORT – PATIENTS ARE NOT GETTING THE HELP THEY NEED



Satisfaction with Neurotoxin

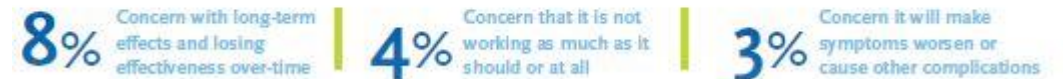
■ Most Common Concerns about neurotoxin

- For those individuals who are currently taking a neurotoxin, we asked “What concerns you the most about your neurotoxin treatment?” The most common answers were:

- **26%: Cost of the Medication**
- **26%: Safety of the Medication**
- **19%: Pain of the Needle**
- **8%: Long term effects and losing effectiveness over time**
- **4%: Concern that it is not working as it should**
- **3% Concern that it will make symptoms worse**



We also included an “Other” category and found that several responses could be grouped into general categories that were not listed on the survey:



THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED

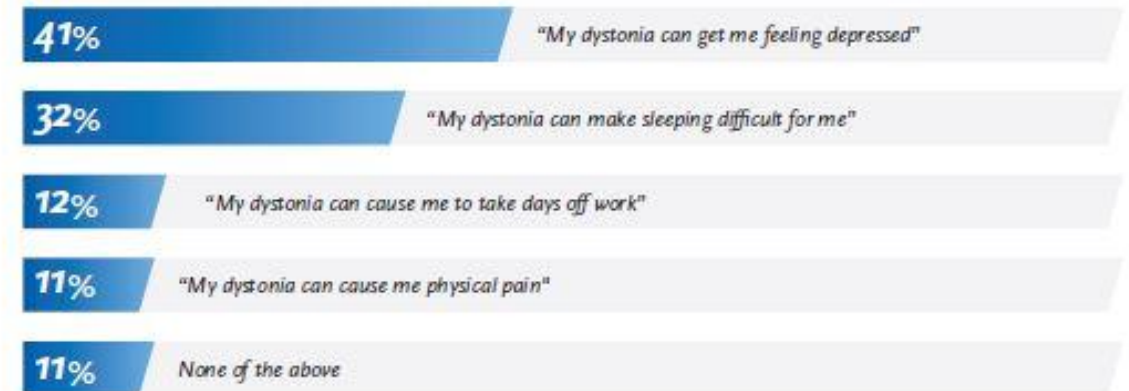


A Painful Existence in Many Forms

We asked survey respondents who were taking a neurotoxin, “As the effect of your injections begins to wear off, which of the symptoms start to re-emerge and affect your day-to-day life and activities”. Please note respondents could provide multiple answers.

“Cervical Dystonia has changed my WHOLE life. Everything is a challenge; from personal grooming to social events, to going grocery shopping.”
– Survey Respondent

We asked How Do Your Symptoms Affect Your Day-to-Day Life and Activities?



THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED



Depression

- The most common symptom that starts to emerge for those neurotoxin users when their injections began to wear off was depression.
- This was reinforced in a follow up question that we asked later in the survey; "*What is the biggest challenge you face with your dystonia?*" The most frequent answer to this question was some form of anxiety and/or depression — this represented 32% of all responders.
- Some patients broke this down further, and specified that this was due to social anxiety and embarrassment to be around people when visibly disabled (13%). Others noted that they felt depressed about losing their ability to do basic tasks they once took for granted (14%).

"A feeling of isolation"

32%

of responders feel the biggest challenge they face with dystonia is anxiety and/or depression.

THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED



Depression

- We analysed the relationship between anxiety and depression against various forms of dystonia. People who listed anxiety and depression in general as their greatest challenge were evenly distributed across different dystonia types.
- However, depression due to loss of abilities was most common among individuals with generalized dystonia (20%), cervical dystonia (16%), and hand dystonia (13%).
- Social anxiety was most significant among patients with dystonia affecting the face, head, or voice.
 - For patients with facial/hemi-facial dystonia (21%), patients with meige syndrome (20%), patients with cervical dystonia (15%), patients with oromandibular dystonia (14%) and patients with laryngeal dystonia (26%) highlighted social anxiety as their greatest challenge.

"Every aspect of day-to-day living and raising a 5 year old with this monster named Dystonia"

THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED



We asked the question; “What is the biggest challenge you face with your dystonia?”

- **32%** said Depression (this included social stress, anxiety, losing your old life, etc.)
 - **21%** Said Pain
 - **22%** Said Posture, Mobility Coordination, or Motor Control
 - **7%** Said Work or Financial Stress”
-
- *In some instances, the challenges were specifically related to the type of dystonia an individual had.*
 - *For example, of the people who complained of vision problems, 77% of them were diagnosed with blepharospasm. The most common challenge for patients with focal (foot and hand) dystonia was issues related to posture, mobility and coordination (58% of focal foot patients, and 42% of focal hand patients).*

THE DYSTONIA CANADA REPORT - PATIENTS ARE NOT GETTING THE HELP THEY NEED



We asked the question; “What is the biggest challenge you face with your dystonia?”

Not Enough Support

- Overall, there is a feeling that there is not enough support for dystonia patients in Canada. There is a feeling of frustration and a call on the DMRF Canada to help raise awareness for dystonia to ensure all those who suffer from the disorder are getting the help they need.

“I think there is very little public info on how debilitating this condition can be. The diagnosis is very empiric and almost nobody knows about dystonia”

THE DYSTONIA CANADA REPORT - WE WANT TO DO MORE



- ***As the only organization dedicated to supporting dystonia patients in Canada, it is our job to do what we can to improve the lives of these patients. We've come a long way – but we need to do more.***

"With research and time we will beat this crippling disease"

"I will overcome this disorder somehow..."

"Thank-you for showing interest in a condition that I often say I would not wish on my worst enemy."

"I feel I have no where left to turn"

With thanks to Merz Pharma Canada for the generous support of this initiative.