2025 Dystonia Canada Survey

Your Voice Shapes the Future of Dystonia Care in Canada

Introduction

The Dystonia Medical Research Foundation (DMRF) Canada is a registered charity whose mission is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well-being of affected individuals and families.

The goal of this survey was to gather key information that will help DMRF Canada and its supporters to:

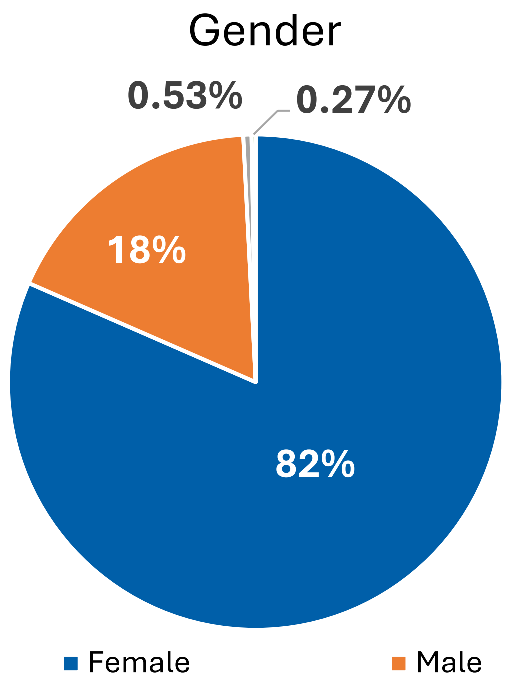
- Advocate for better support, programs, and initiatives.
- Strengthen the voice of the dystonia community nationwide.
- Guide evidence-based decisions that improve lives.

Survey data was collected from March – June 2025. There were 374 responses to this survey. Graphics contain the responses of all 374 respondents unless stated otherwise.

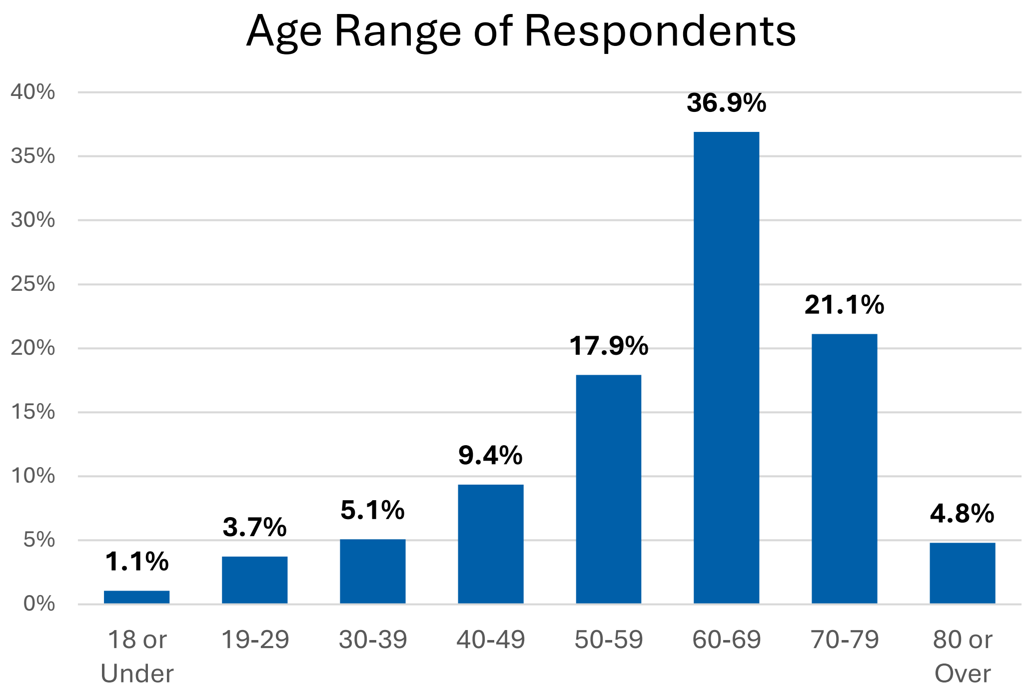
Respondents' Demographics

Key Findings:

- Females make up the majority of the responses.
- Respondents 60 years and older account for more than 60% of responses.



Gender

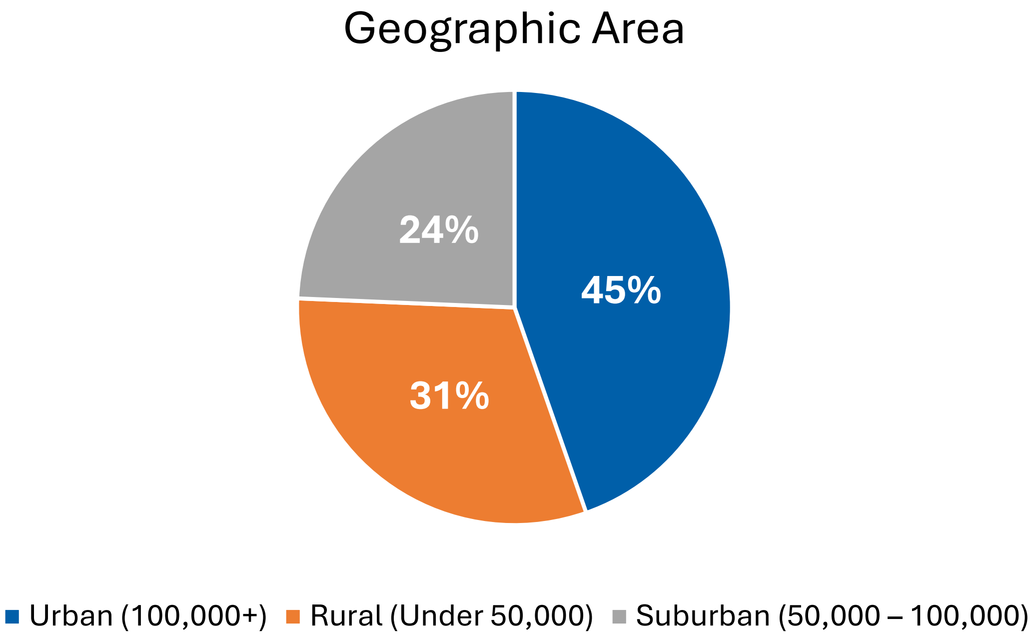


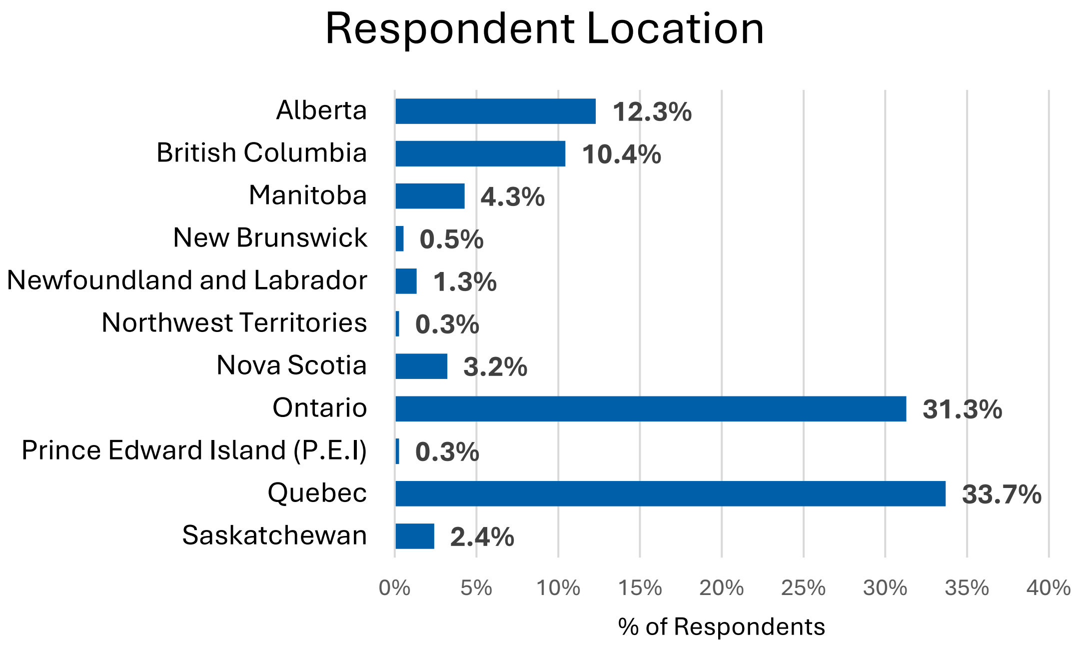
Age Range of Respondents

Respondents' Location

Key Findings:

- Urban respondents were the largest group at 45%.
- Rural respondents were the second largest group at 31%.



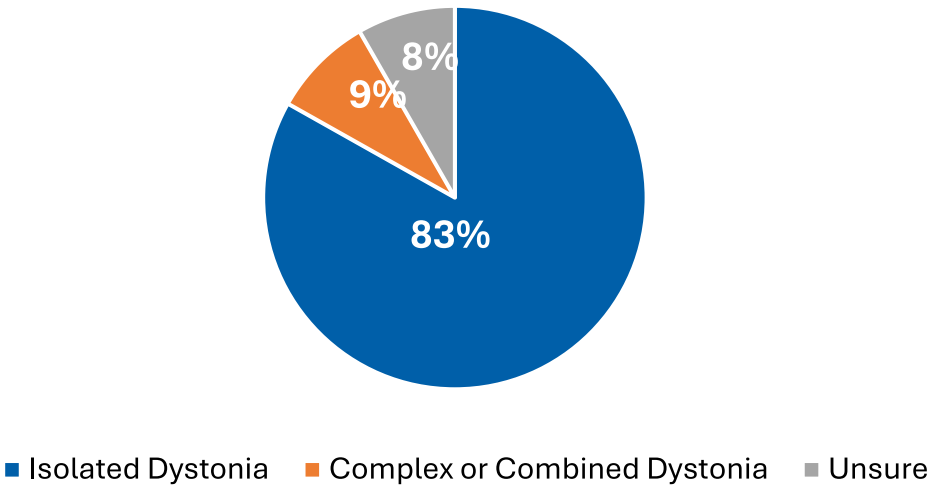


Dystonia Diagnosis

Key Findings:

- Most respondents are diagnosed with isolated dystonia. Complex/combined diagnoses are a small minority.
- Cervical Dystonia is the most common form with 69%.

Type of Dystonia

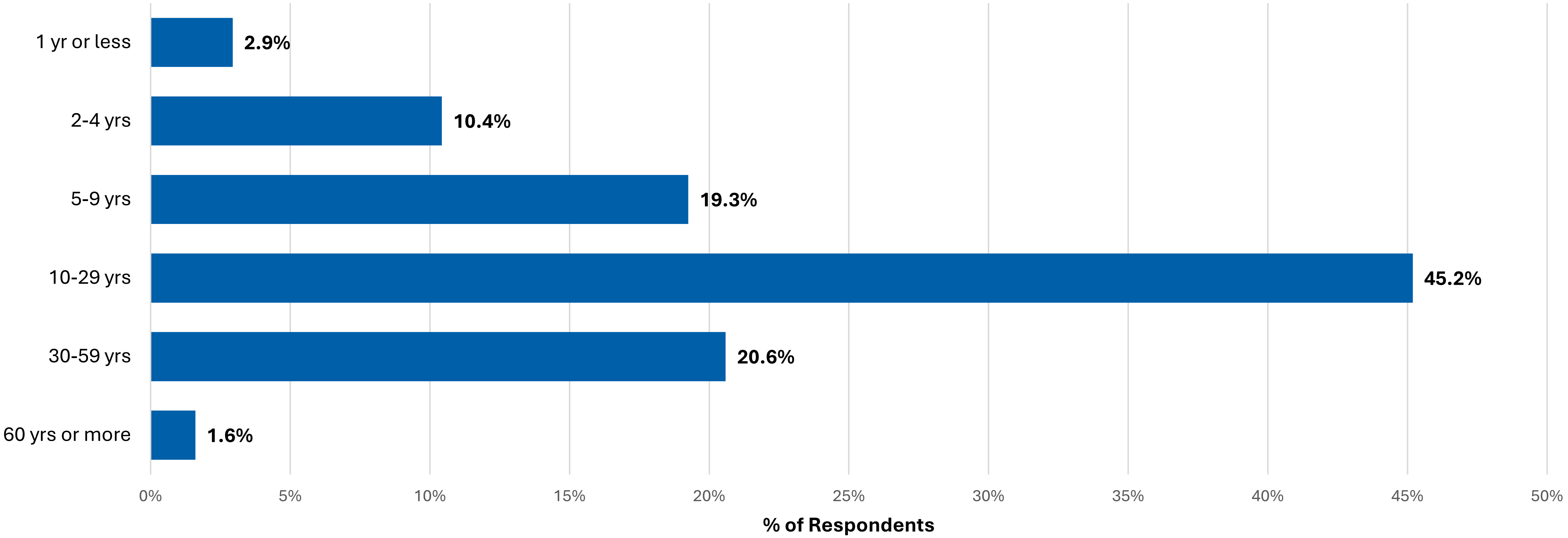


Which specific forms of dystonia have you been diagnosed with?	**% of Respondents**
Cervical Dystonia	68.7%
Blepharospasm	12.3%
Other	10.4%
Laryngeal (Spasmodic) Dystonia	9.9%
Generalized Dystonia	8.8%
Oromandibular Dystonia	8.0%
Writer's Cramp (Hand Dystonia)	6.7%
Lower Limb Dystonia	3.5%
Myoclonus Dystonia	3.2%
Dopa-responsive Dystonia	2.9%
Focal Hand Dystonia in Musicians	2.1%
Functional Dystonia	1.6%
Trauma-induced Dystonia	1.3%
Paroxysmal Dystonia & Dyskinesias	1.1%
Pediatric Dystonia (Children)	1.1%
Drug-induced (Tardive dyskinesias, Acute Dystonia, Tardive Dystonia)	0.8%
Embouchure Dystonia (Musicians)	0.8%
Neurological and Metabolic Diseases (Dystonia occurring as part of another disorder or condition)	0.5%
Rapid-onset Dystonia-Parkinsonism	0.5%

Years Living with Dystonia

Key Findings:

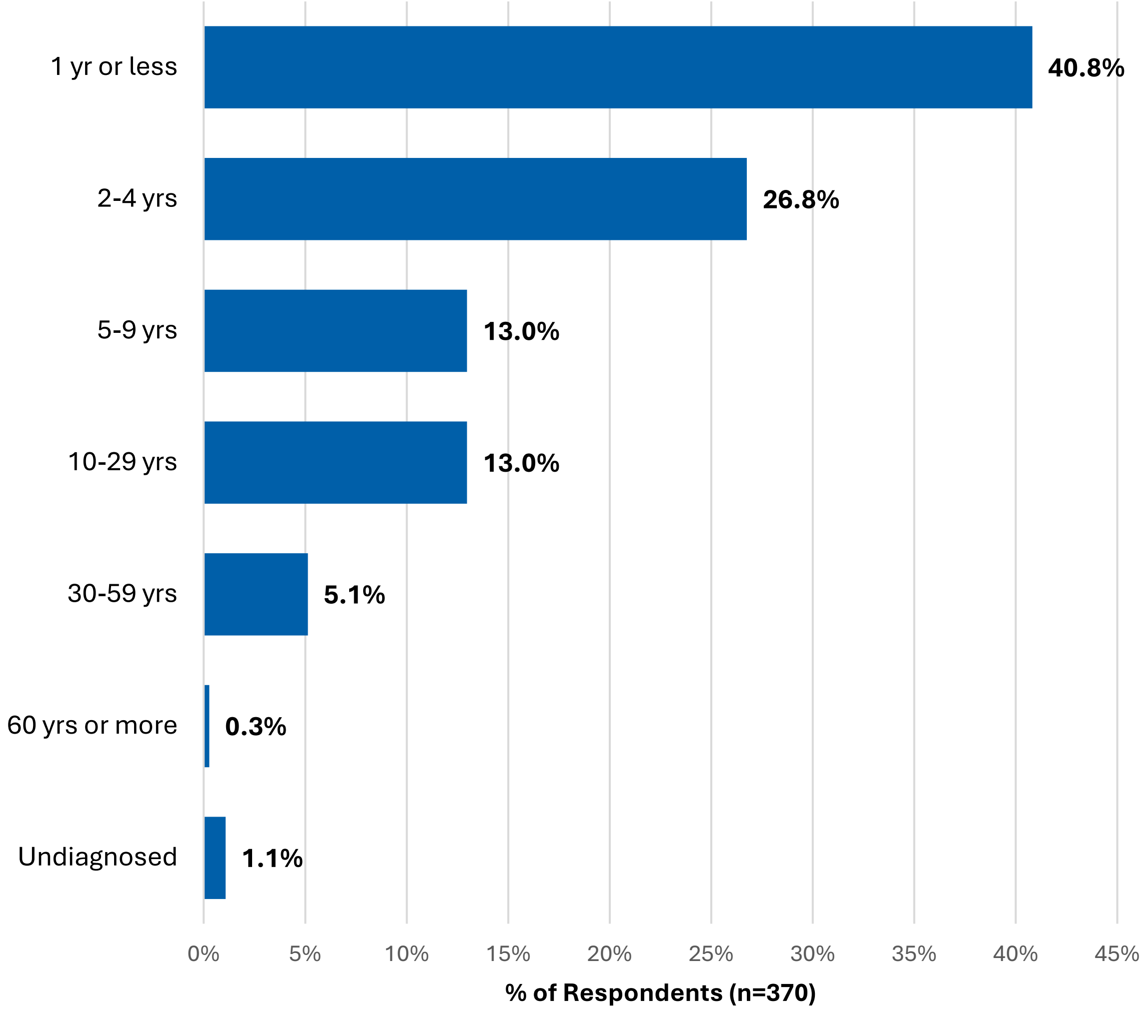
- Majority (67%) of respondents have been living with Dystonia for more than 10 yrs.



First Symptom to Dystonia Diagnosis

Key Findings:

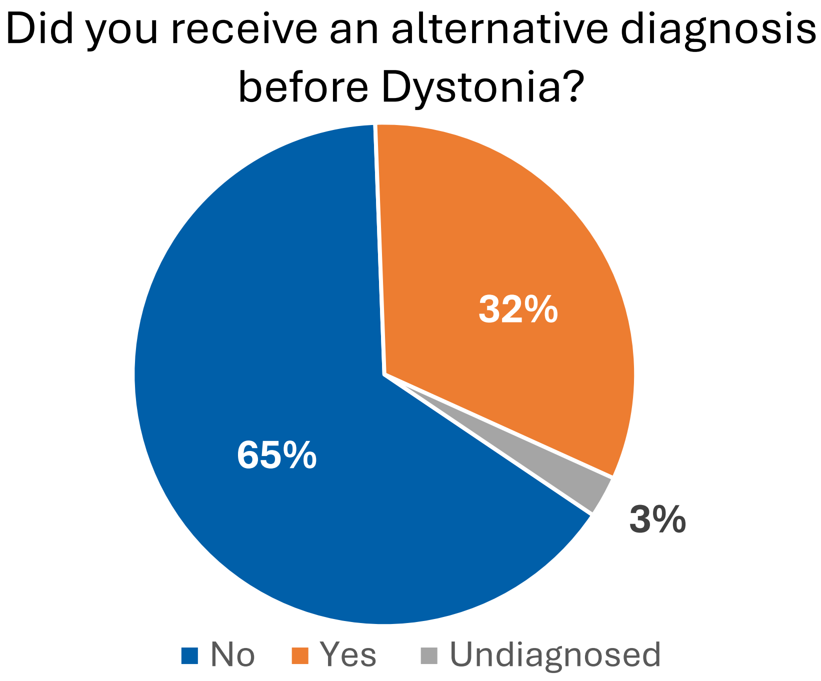
- 41% of respondents received a dystonia diagnosis within the first year of experiencing symptoms. This indicates better awareness especially within the medical community.
- 31% of respondents took 5 years or more to receive a diagnosis.
- Of those who reported 10+ years to diagnosis, majority were over the age of 50 yrs.



Respondents’ Initial Diagnosis

Key Findings:

- Most respondents (65%) received an initial diagnosis of dystonia.
- For the 32% of those not initially diagnosed with dystonia, tremors and mental health disorders were the most common prior diagnoses.

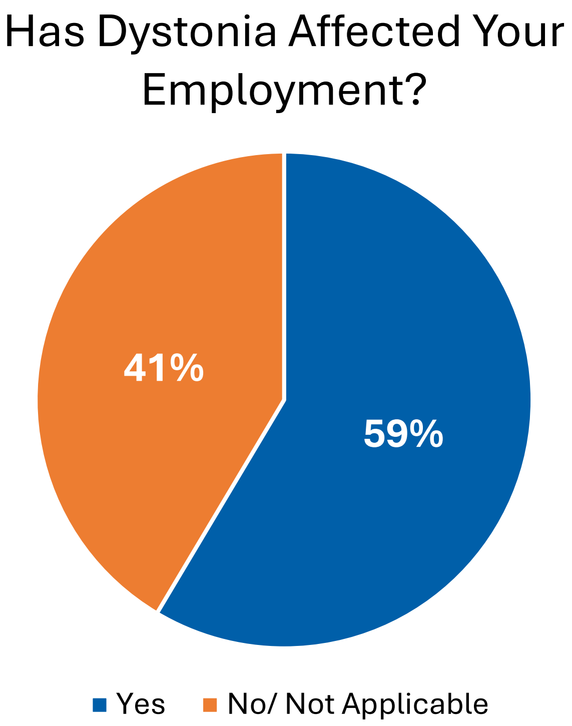


Alternate Diagnosis Received (Ranked by Frequency)
Tremors
Anxiety
Stress
Muscle Tension
Arthritis
Dry Eyes
Fibromyalgia
Scoliosis
Parkinson's Disease
Tendonitis
Chronic Fatigue

Effect of Dystonia on Employment

Key Findings:

- Majority of respondents (59%) stated that Dystonia has negatively impacted their ability/capacity to work.
- 35.3% respondents are working, while 12.3% are unable to work.



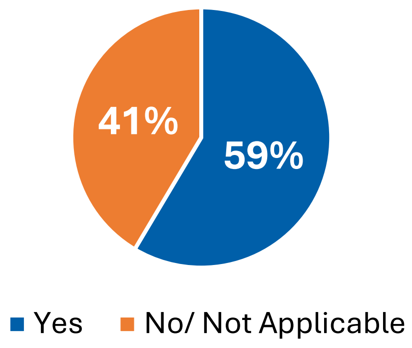
Employment status	% of Respondents
Retired	47.6%
Employed full-time (30 hrs. or more per week)	21.1%
Unable to work	12.3%
Employed part-time (Less than 30 hrs. per week)	8.6%
Self-Employed	5.6%
Student	2.1%
Homemaker	1.1%
Unemployed & looking for work	1.1%
Unemployed & NOT looking for work	0.5%

Effect of Dystonia on Employment

Key Findings:

- Most respondents stated that dystonia affects their ability to work, mainly because symptoms limit the fine motor skills needed for their job.
- Respondents also reported reducing work hours due to pain or discomfort from staying in one position too long.

Has Dystonia Affected Your Employment?



Top 3 Employment Impacts of Dystonia:

- Reduced Work Capacity / Early Retirement
- Physical Limitations on the Job
- Need for Accommodations or Disability Support

Direct Quotes:

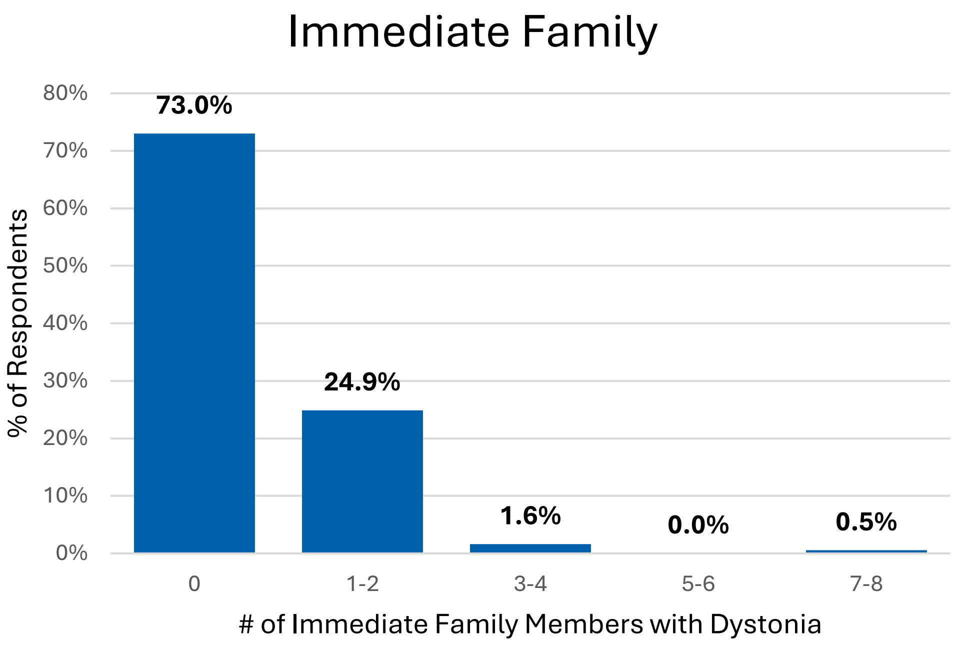
“I had to give up my career due to my dystonia.”

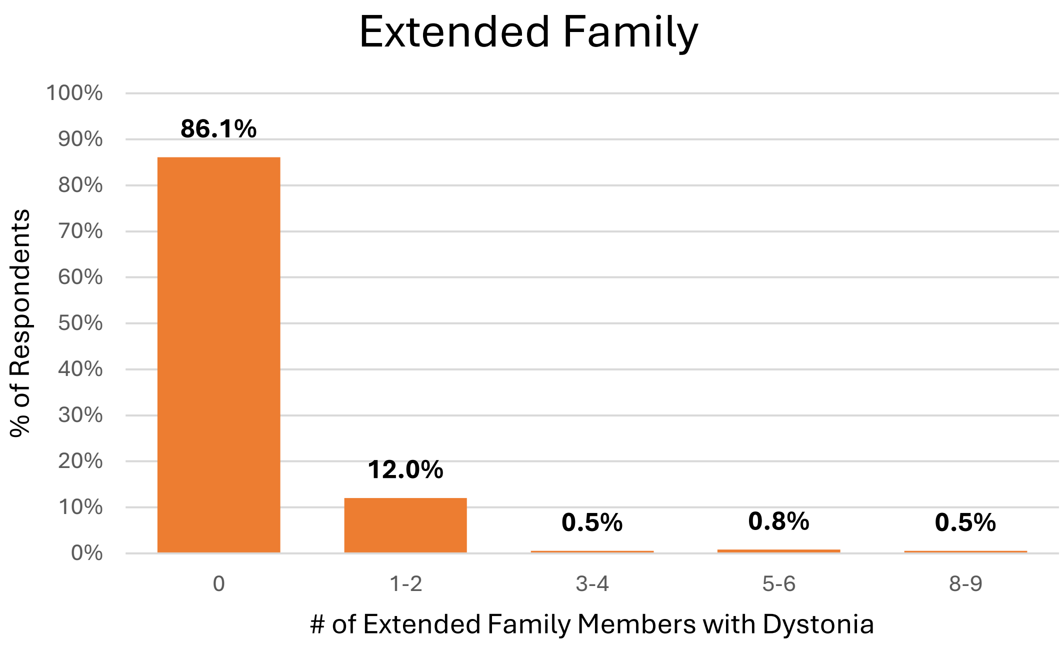
“I was forced onto long-term disability because I simply couldn’t keep up.”

Family History - Dystonia

Key Findings:

- Majority of respondents do not have family members with dystonia.
- At least 27% of respondents report a family member with dystonia.



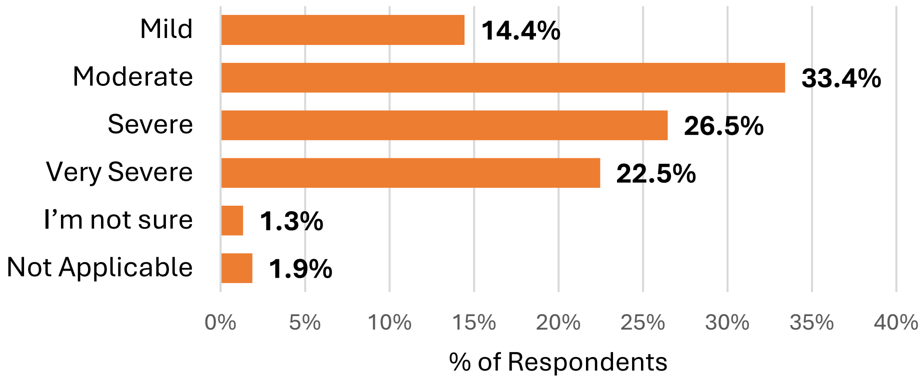


Dystonia Symptom Severity

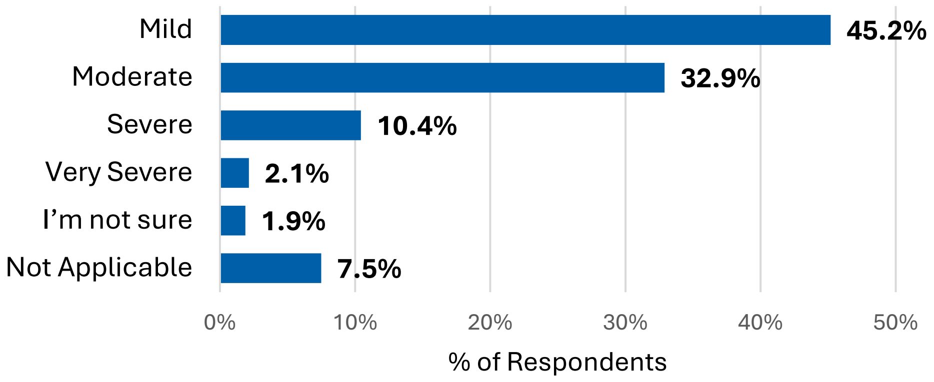
Key Findings:

- Most respondents (49%) described their untreated dystonia as severely disabling.
- With treatment, respondents reporting severe/very severe disability decreased from 49% to 12% (−36 percentage points).
- Despite treatment, 45% reported moderate-to-severe disability.

How would you describe the severity of your disability caused by dystonia WITHOUT treatment



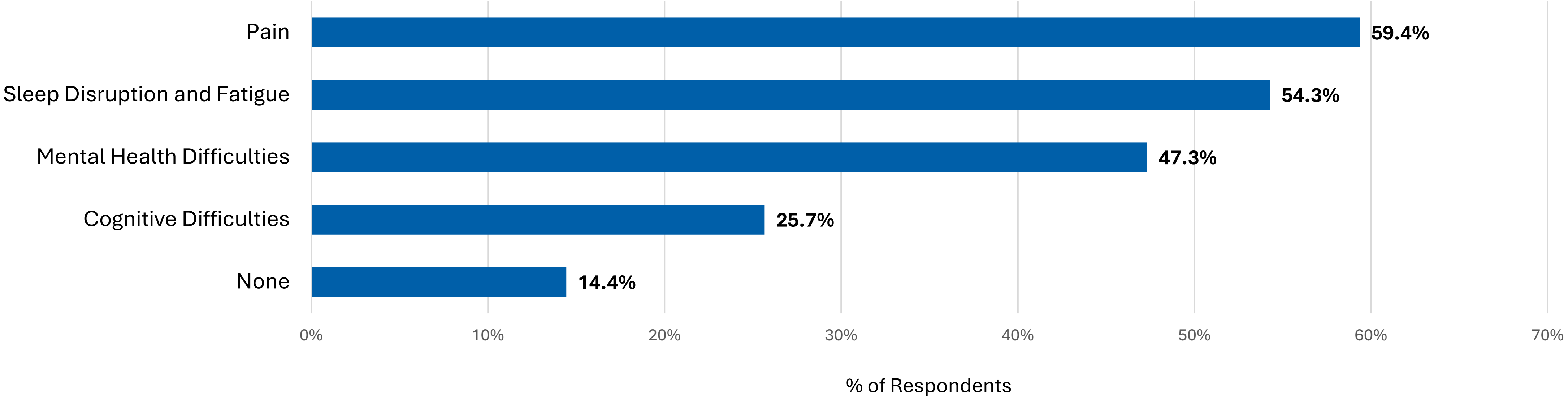
How would you describe the severity of your disability caused by dystonia WITH Treatment



Dystonia Non-Motor Symptoms

Key Findings:

- Pain, fatigue, and mental health difficulties were common non-motor symptoms.
- A few (14%) reported no non-motor symptoms at all.
- The top three reported mental health difficulties were anxiety, depression, and isolation/social withdrawal.

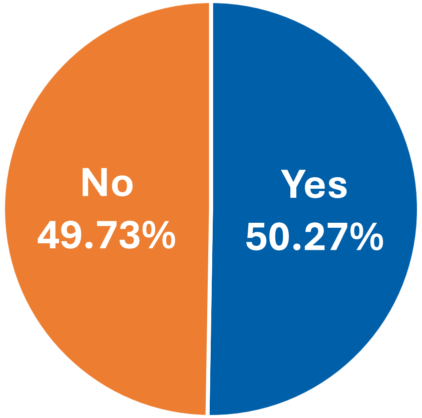


Healthcare Experience

Key Findings:

- Over 50% of respondents reported they were not taken seriously by a healthcare provider, often citing misunderstandings, stigma, or misdiagnosis.
- Long wait times were reported among the most common challenges in accessing treatments, though a significant number reported no major barriers.

Have you ever felt that a healthcare provider did not take your dystonia symptoms seriously?



Direct Quotes:

“A neurologist told me that I might have a rare condition called dystonia. She said she would refer me however also told me chances were very low that I had dystonia and that it would be a waste of OHIP [Ontario Health Insurance Plan] Money if I did not have dystonia. I did not accept the referral because I did not want to be a waste of money.”

"Family doctor made me feel like I was crazy, told me to do yoga, get a smaller purse to carry rather than my big purse.“

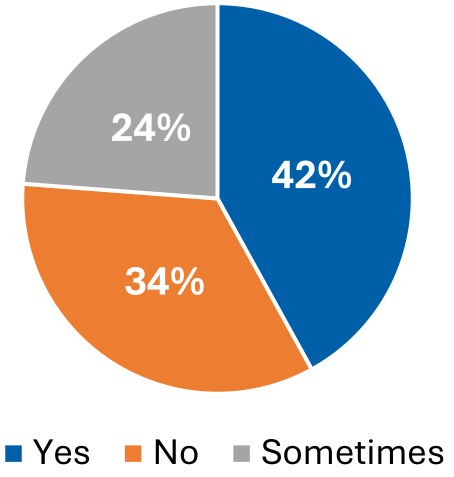
"I was told I had the symptoms because I didn't want to work."

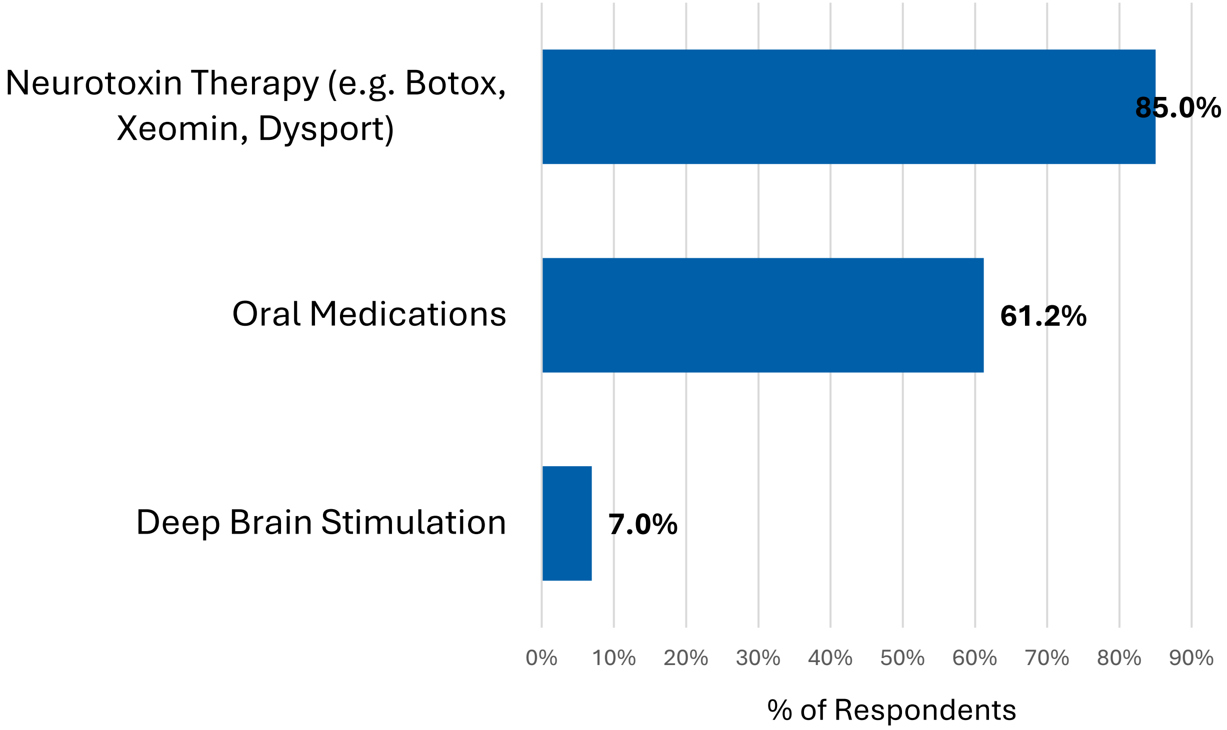
Treatment Types, Plan and Management

Key Findings:

- Less than 50% of respondents consistently receive a treatment plan from their healthcare provider.
- Only about 1/3 of respondents reported that their treatment plan was regularly reviewed.
- Neurotoxin therapy is the most common treatment type received by respondents.

When you see your healthcare provider, are you provided with an overall dystonia treatment plan or goal for managing your dystonia?



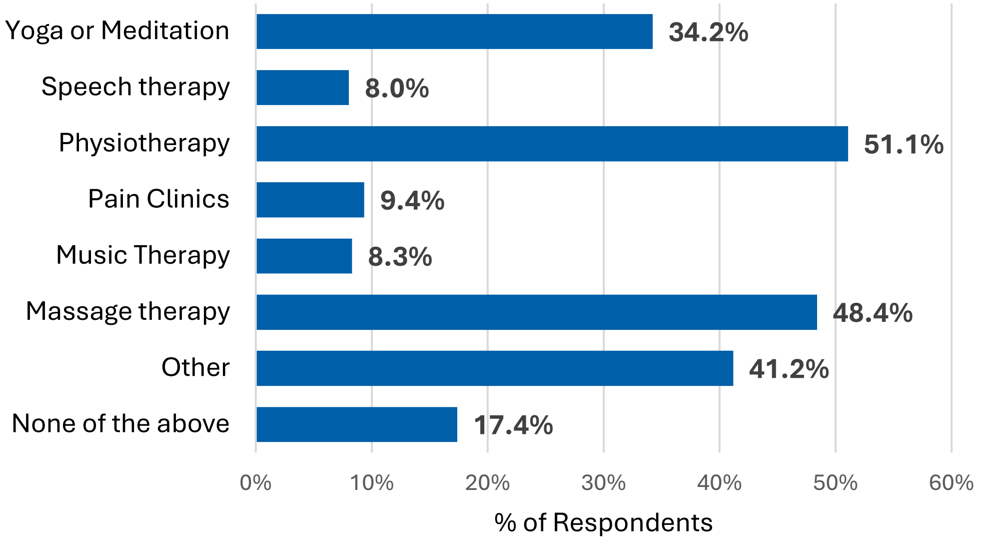


Complementary Therapies

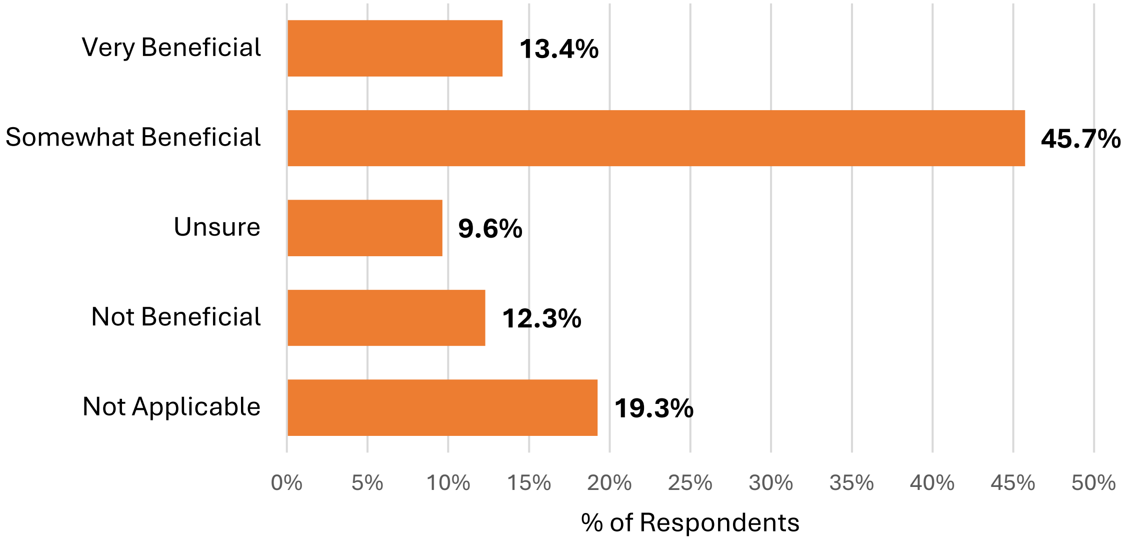
Key Findings:

- Physiotherapy (51%) and massage therapy (48%) are the most used therapies
- Among “Other” therapies, the most frequent mentions were chiropractors, exercise, and acupuncture.
- Most respondents felt complementary therapies were somewhat beneficial (45.7%), with fewer reporting very beneficial (13%) or not beneficial (12%).

Types of Complementary Therapies Used



Perceived Benefit of Complementary Therapies

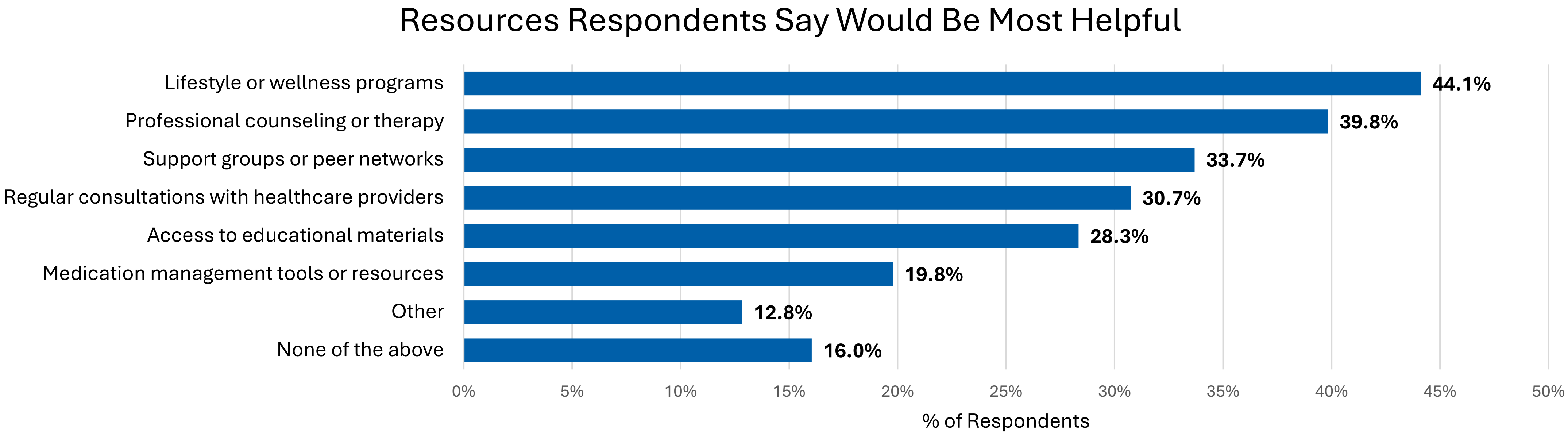


Resources and Supports

Dystonia Medical Research Foundation Canada
Fondation de Recherche Médicale sur la Dystonie Canada
serving all dystonia-affected persons
désservant toutes personnes atteintes de dystonie

Key Findings:

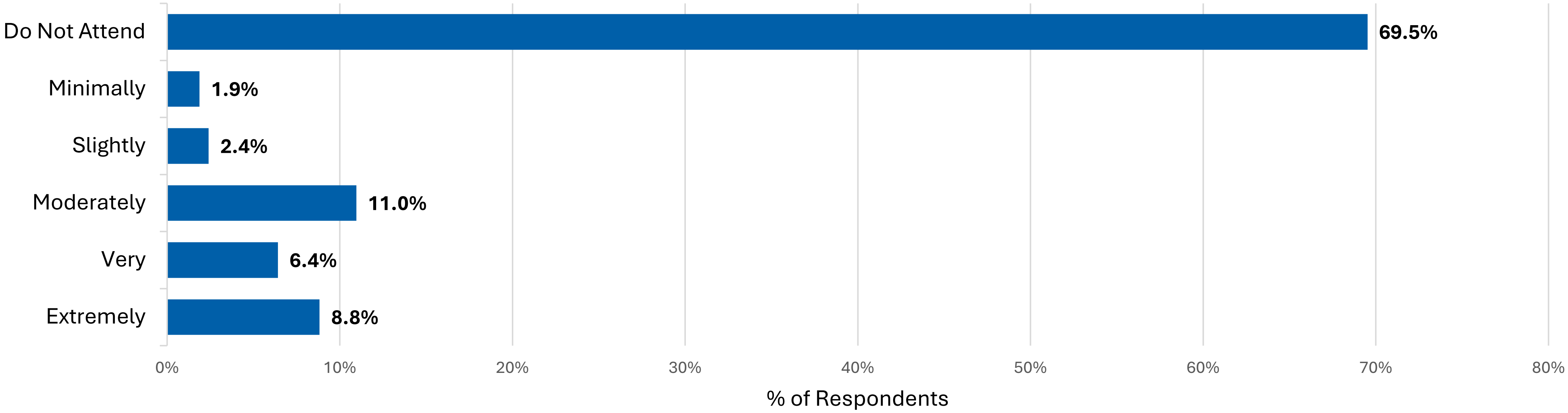
- **Self-management & Lifestyle:** Lifestyle/wellness programs rank #1 (44%); access to educational materials is also notable (28%).
- **Clinical & Professional Support:** Professional counseling/therapy ranks #2 (40%); regular consultations remain important (31%).
- **Community & Peer Support:** About one-third want support groups or peer networks (34%).


Resources Respondents Say Would Be Most Helpful

Perceived Benefit of Expert-led Education Sessions for Patients

Key Findings:

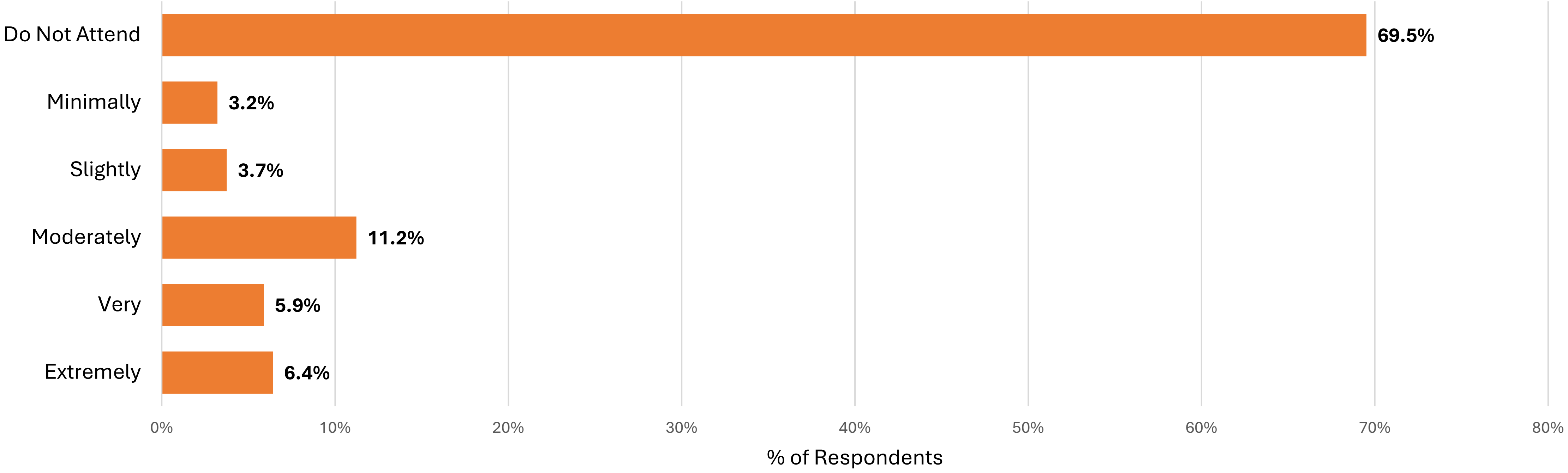
- 70% do not attend expert-led patient education sessions.
- 31% attend; of those, 86% rate them moderately to extremely beneficial (27% of all respondents).
- “Moderately beneficial” is the most common rating among attendees (~36%).



Perceived Benefit of Support Group Meetings

Key Findings:

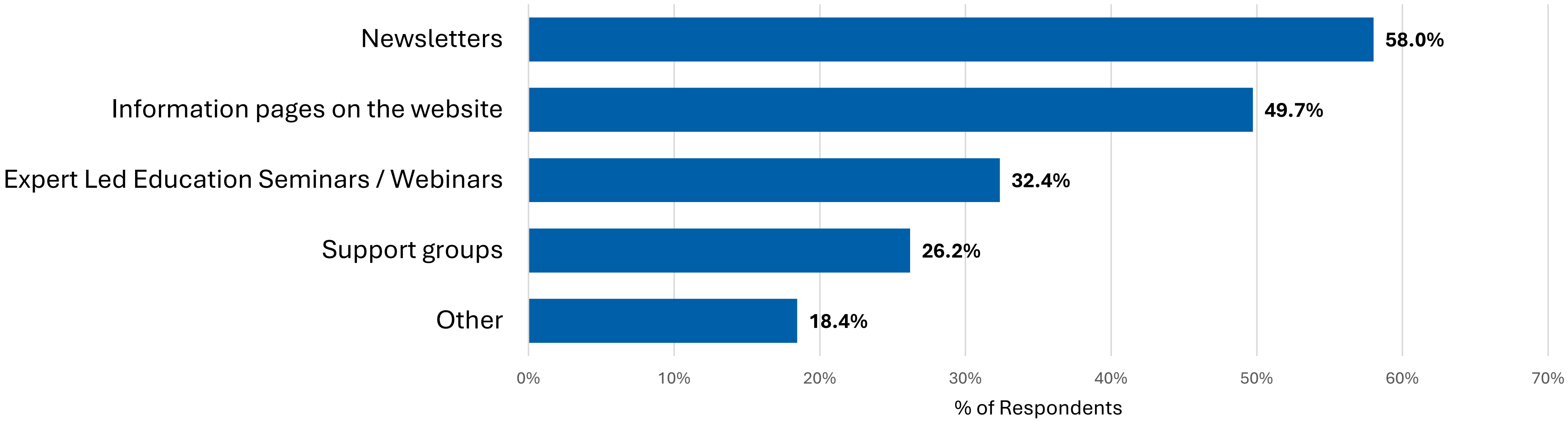
- 70% do not attend support group meetings.
- 30% attend; of those, 77% rate them moderately to extremely beneficial (≈24% of all respondents).
- Among attendees, “moderately beneficial” is the most common rating (≈37% of those who attend).



Usage of DMRF Canada Resources

Key Findings:

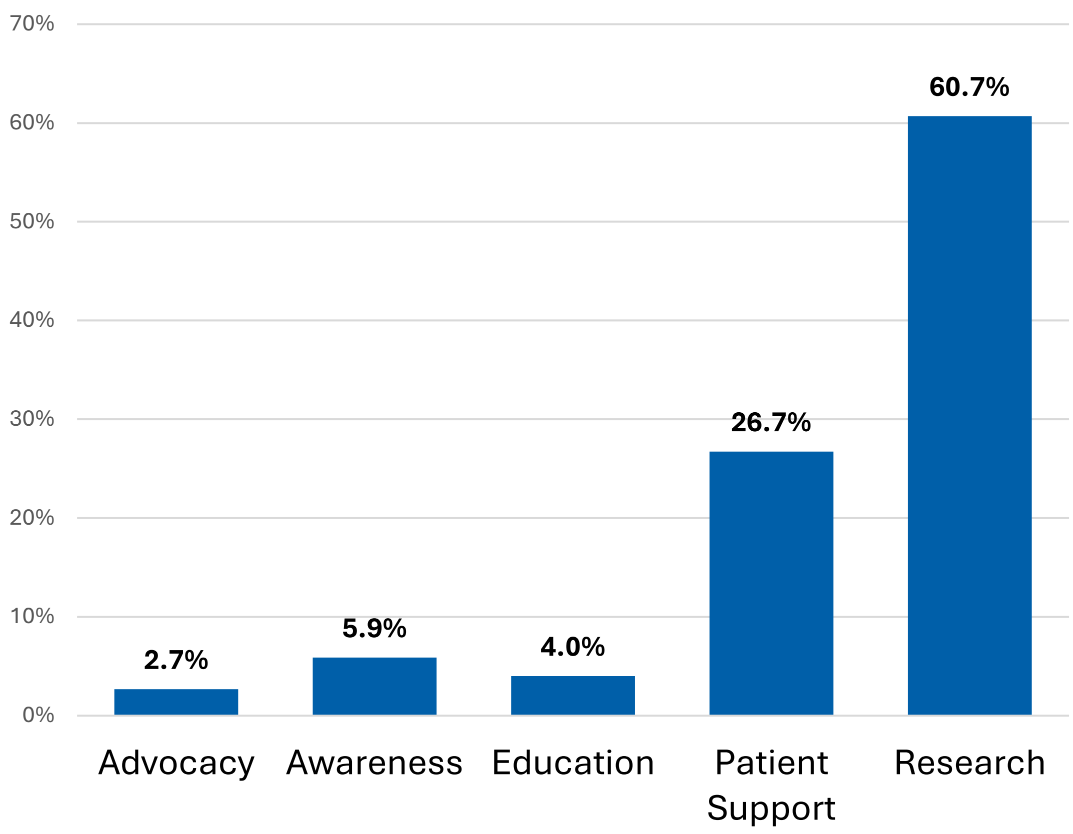
- Newsletters are the most used (58%) DMRFC resource by respondents.
- Digital information—website pages (49%) and expert-led webinars/recordings (32%)—is widely used.
- Under “Other,” respondents mostly cited they are new/unaware of DMRF Canada.



DMRF Canada Priorities Ranked by the Dystonia Community

Key Findings:

- Dystonia research was ranked the highest importance (61%).
- Patient support ranks a distant second (27%).
- Awareness (6%), education (4%), and advocacy (2%) together account for 12% of top priorities.



Turning Insights into Action

We want to thank all those who responded to our 2025 Dystonia Canada Survey giving us insight into what our members would like to see.

The survey is helping us in various ways by:

- Building clear evidence of the needs of the dystonia community.
- Advocating to multiple levels of government and secure funding to address critical gaps.
- Shaping programs and initiatives that matter most to people with dystonia.

Turning Insights into Action – Research

Over 60% of survey respondents said research is their top priority.

➞ **Our Response**

- We’re doubling down on advancing dystonia research. This includes funding our Clinical and Research Fellowship, as well as supporting the 2025 DMRF Grant and Fellowship programs.
- We’re also encouraging the community to participate in research studies listed on our website to help accelerate progress. www.dystoniacanada.org/clinical-trials-for-dystonia

Turning Insights into Action – Medical Community Education

More than half of respondents reported that their symptoms were not taken seriously, often due to a lack of knowledge among healthcare providers.

➞ Our Response

We're investing in education and training for medical professionals. In 2025 alone,

- We sponsored the 2025 Pan American Movement Disorders Neurophysiology Course and the 2025 Canadian Movement Disorders Course, to improve expertise and education within the medical community.

- We also partnered with Patient Voice, during the *September 2025 Awareness Month,* on a campaign to improve general understanding and diagnosis of dystonia.

Turning Insights into Action – Patient Advocacy and Support

48% of respondents said they do not feel they have the strategies they need to communicate effectively with their doctors.

➞ Our Response

- We’ve created new tools to help patients navigate treatment and collaborate with healthcare providers.
- Resources like *Setting Treatment Goals with Your Healthcare Provider* and *Nonmotor Symptoms of Dystonia* brochures are now available to support patients in managing their dystonia and advocating for their needs.

Acknowledgement

This survey was made possible through the support of the medical student volunteers from the Community-Based Service-Learning (CBSL) program, part of the Health in Community (HC) team at the University of Toronto Temerty Faculty of Medicine. We thank students Afreen Ahmad and Erin Day for their contributions.

We gratefully acknowledge AbbVie and Ipsen for supporting this project and its dissemination to the dystonia community.

www.dystoniacanada.org/Survey2025

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