

# UNDERSTANDING DYSTONIA

Summer 2009

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## WE MOVE RESEARCH REPORT

### Understanding Dystonia

Dystonia is a hyperkinetic movement disorder characterized by sustained muscle contractions, usually producing repetitive and twisting movements and abnormal postures or positions.

Dystonia can affect people of all ages. It can manifest in one, several or many body parts; it can be primary or secondary; and although several genes have been identified, most cases of dystonia are idiopathic. Dystonia is generally classified in three ways: age of onset; bodily distribution of symptoms; and cause.

There are currently no known treatments that can reverse the course of primary dystonia. However, symptoms may be managed well with a combination of therapies. There are three main approaches to the treatment of dystonia: oral

medications; injections of botulinum toxin or phenol; and surgery. Physical therapy may play a role for some patients, most often as a supplement to other therapies.

The number of people in the United States living with dystonia is estimated to be 300,000 but dystonia is generally considered to be underdiagnosed.

Although individuals with dystonia may have access to therapy and primary care through local clinics, hospitals or schools, they may not have the information or access to the most current technologies in medical management. Many primary care and rehabilitation providers in local communities have limited information access and resources to refer clients or offer current technologies in

therapeutic management, such as chemodenervation with botulinum toxin, neurolysis with alcohol or phenol, physical and occupational therapy rehabilitation techniques; surgical interventions; and innovative combination therapies.

#### Dystonia is classified by:

- Age of onset
- Bodily distribution
- Cause

#### Inside this issue:

Patient-Physician Relationship	2
Satisfaction with Health & Management	3
Patient Understanding of Dystonia	3
The Impact of Dystonia	4
The Most Troubling Symptoms of Dystonia	5
About This Research	5
Therapies Utilized to Manage Dystonia	6
The Side Effects of Dystonia Therapy	7



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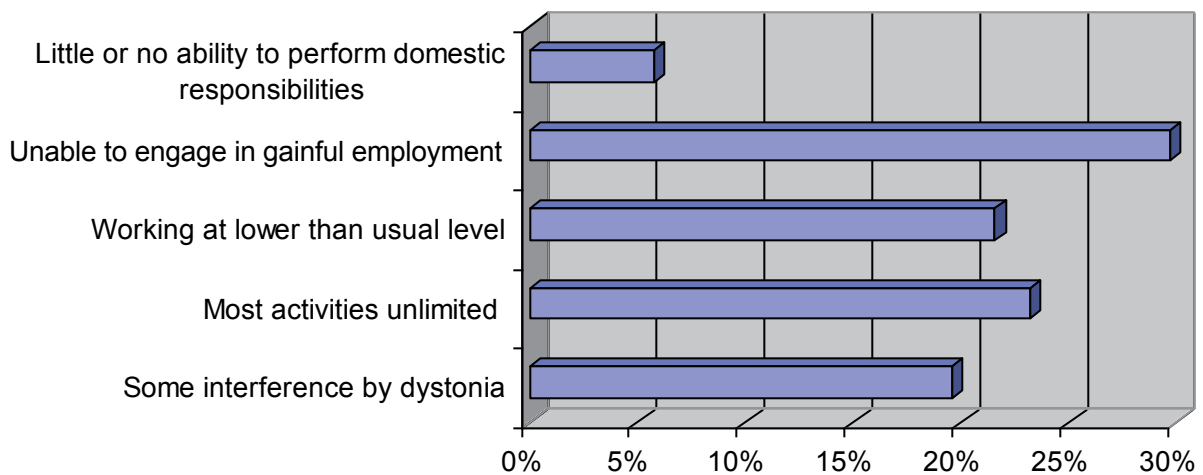
## The Impact of Dystonia

The survey explored the impact of dystonia on employment, activities of daily living (ADLs), activities outside the home, employment and driving. Almost 28% of respondents indicated that they are unable to engage in voluntary or gainful employment as a function of their dystonia. This was the most frequently named response and was fairly consistent across all categories of dystonia with the exception of spasmodic dysphonia. Only 5.6% of respondents stated that there was no difficulty caused by dystonia with regard to their employment.

When questioned about the impact of dystonia on activities of daily living, 29.6% of survey respondents indicated that their activities at home were unlimited but there was some interference by dystonia. Only 1.2% indicated that they were dependent on others for most self-care tasks.

Survey respondents were also questioned about their ability to carry out activities outside the home. Thirty percent of respondents selected this response: "Unlimited activities but bothered by dystonia," while 23.6% selected this response: "Limited activities outside the home and certain activities became impossible or were given up because of my dystonia."

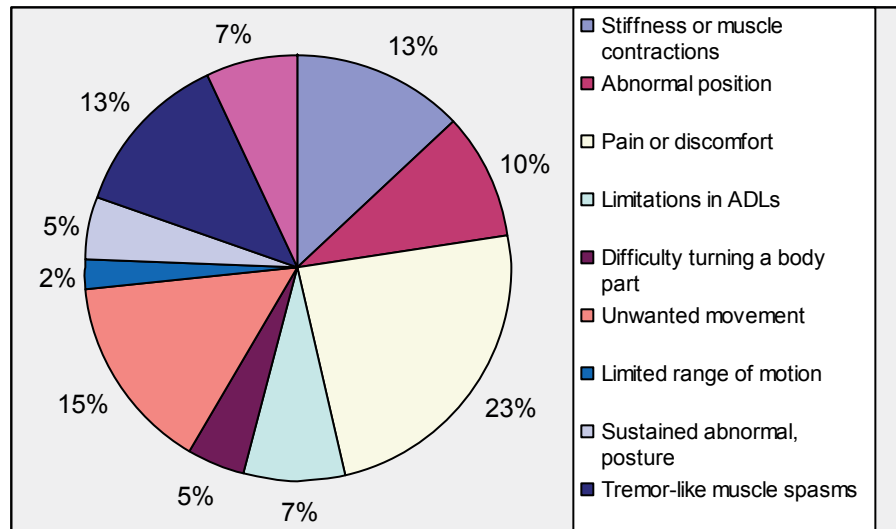
### Dystonia and Employment



## The Most Troubling Symptoms of Dystonia

When asked to name just one symptom—the one with the greatest negative impact on their quality of life (QOL)—people living with dystonia reported a basically uniform or consistent finding.

Twenty-three percent of survey respondents named “pain or discomfort” as the most disabling symptom. “Unwanted movement” was indicated by 15% of respondents; “stiffness or muscle contractions” by 13%; and “tremor-like muscle spasm” by 13%.



There are a number of symptoms associated with dystonia. Please indicate which aspect of this disorder has the most significant impact on the quality of your life. Please choose ONE.

## About This Research

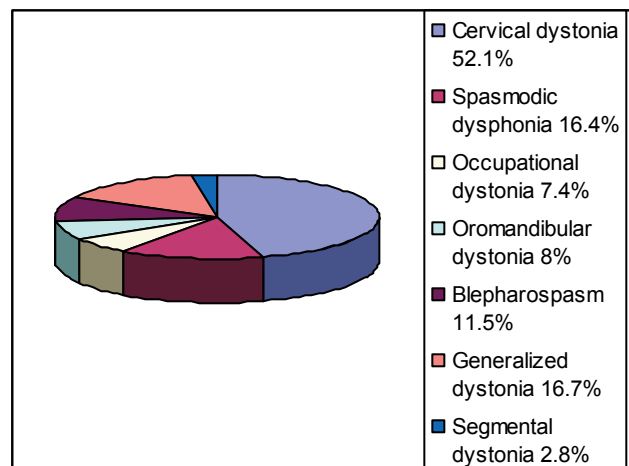
The data presented in this report were collected via an online survey posted on [www.wemove.org](http://www.wemove.org) from December 3, 2008 through April 15, 2009. This survey was completed by 1,007 people. Of these respondents, 859 had a confirmed diagnosis of dystonia.

Respondents to the dystonia survey declared a mix of dystonia types: 52.1% cervical dystonia; 16.4% spasmodic dysphonia; 11.5% blepharospasm; 8% oromandibular dystonia; 7.4% occupational dystonia; 16.7% generalized dystonia; and 2.8% segmental dystonia.

The goal of this survey was to describe the experience of people living

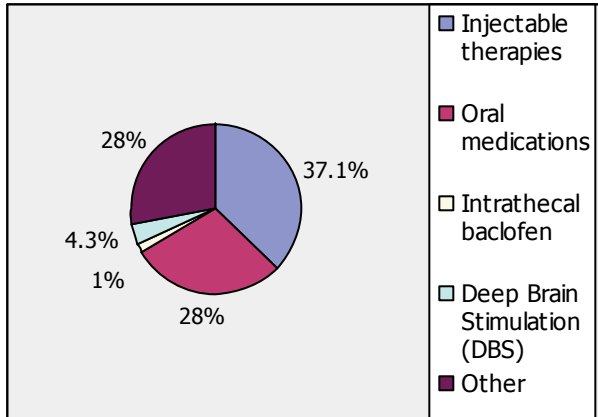
with dystonia. The participants were limited to people living in the United States.

WE MOVE wanted to hear from the dystonia community about: types of physicians that care for people living with dystonia; the nature of patient-physician relationships; and the impact of dystonia on activities of daily living (ADLs), employment and overall perception of health. The types of medications utilized and the patient perspective of their effectiveness and drawbacks were also overviewed. These data were gathered for the purpose of knowledge gap identification for future WE MOVE educational initiatives.



What type of dystonia do you have?

### Therapies Utilized to Manage Dystonia



What medications, medical devices or injectable therapies do you utilize to manage the symptoms of dystonia?

Survey respondents were asked to name the oral medications, medical devices or injectable therapies utilized to manage the symptoms of dystonia. "Injectable therapies such as botulinum toxin or phenol" was named most frequently (37.1%). Almost 30% of respondents identified oral medications as a management tool.

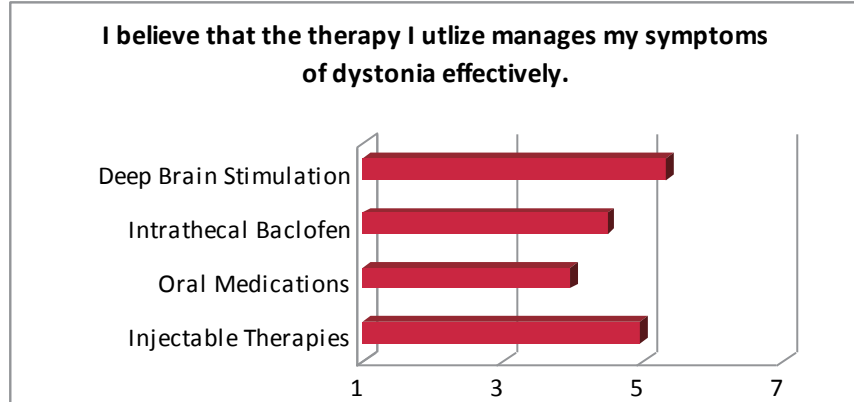
Another almost 30% indicated that they were not utilizing medications, medical devices or injectable therapies to manage their dystonia.

Respondents were asked to assess their degree of agreement with the statement: "I believe that the <therapy type> I utilize manage my symptoms of dystonia effectively." This response was tabulated for injectable therapies, oral medications, intrathecal baclofen and deep brain stimulation.

When these responses were analyzed against a scale of 1 to 7 (1 being "Strongly disagree" and 7 being "Strongly agree"), the average degree of satisfaction for therapy type was determined. People living with DBS (n=14) demonstrated the highest degree of satisfaction with over three-quarters of respondents claiming some degree of satisfaction; more than one-third of these respondents are very satisfied.

The "average" user of injectable therapies (n=329) is somewhat less than satisfied with the efficacy they experience. Many of these patients (39.5%) indicated that they "somewhat agree" that their symptoms are managed effectively. However, when all levels of agreement are combined, 76.6% of these patients demonstrated some degree of satisfaction.

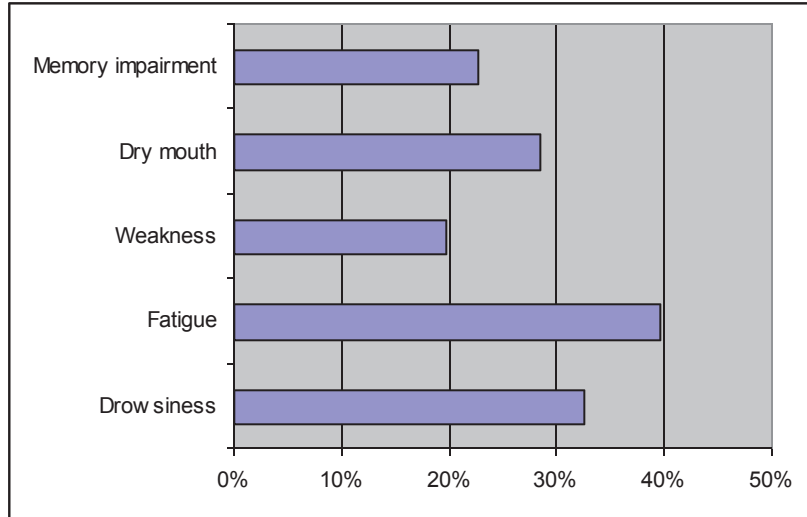
Users of intrathecal baclofen (n=12) appeared to be generally satisfied with this therapy.



Please indicate your degree of agreement with the following statement: "I believe that the injectable therapies/oral medications/ITB I utilize manage my symptoms of dystonia effectively." (1 totally disagree/7 totally agree)

## The Side Effects of Dystonia Therapy

Most therapeutic approaches to the treatment of dystonia including oral medications, injectable and surgical therapies, have side effects. These side effects vary greatly from treatment to treatment and from patient to patient. Almost 40% of survey respondents named fatigue or drowsiness as a side effect of the therapy they utilize. Other side effects associated with the therapies utilized to manage dystonia included dry mouth, memory impairment, weakness and others.



Please indicate the side effects you experience from the medication, medical devices or therapies you currently utilize to manage the symptoms of dystonia.

[www.wemove.org](http://www.wemove.org)

### WE MOVE

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WE MOVE is a not-for-profit organization that utilizes creativity, innovation, and collaborative approaches to improve awareness, diagnosis, and management of movement disorders among people living with these conditions and the professionals who care for them.



*WE MOVE gratefully acknowledges funding for this survey from Merz Pharmaceuticals.*

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### Patient-Physician Relationship

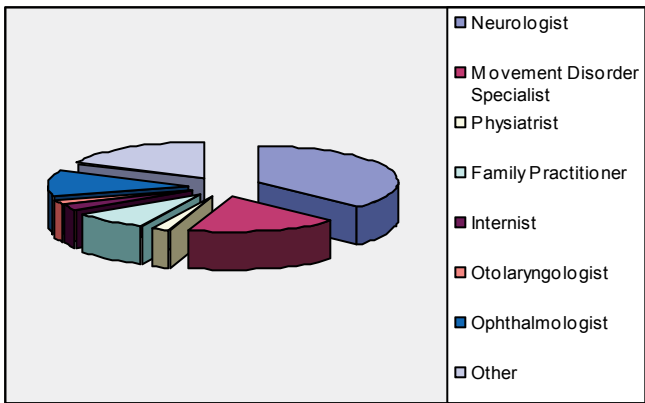
The majority of survey respondents (74%) are under the care of a neurologist. Thirty-two percent of the sample indicated that movement disorders specialists are involved in the management of their dystonia. Primary care physicians (family practice at 13.2% and internal medicine at 3.7%) were named by 16.9% of the respondents. Psychiatrists (physical medicine and rehabilitation specialists) were named by 5.9% of patients. Other specialties noted included

ophthalmologists (2.3%) and otolaryngologists (1%).

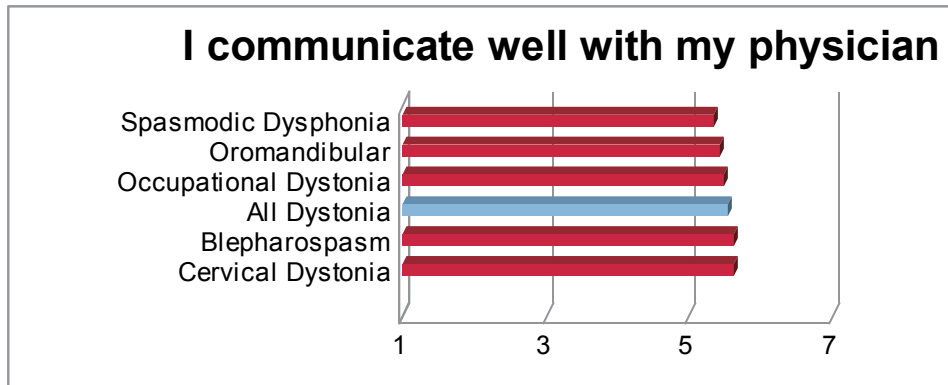
Eighty-two percent of respondents, regardless of the type of dystonia, indicated that they communicate well with their physicians and that their physicians take the time to explain dystonia and its management.

Patients under the care of movement disorder specialists and neurologists presented a slightly more favorable assessment of the patient-physician relationship

than those under the care of a psychiatrist, otolaryngologist or ophthalmologist.



What type of physician helps you manage the symptoms of dystonia?

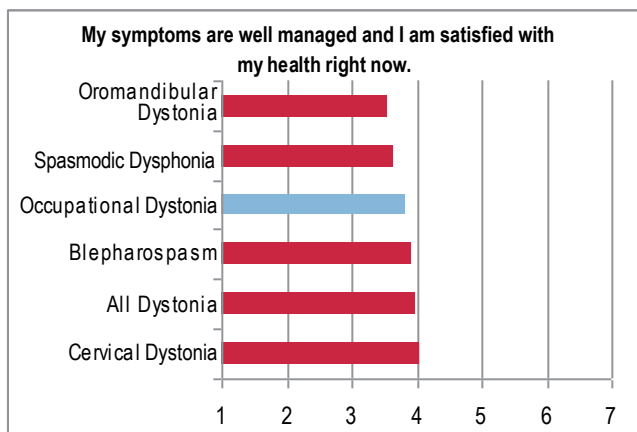


Please indicate how strongly you agree with the statements, "I communicate well with my physician. All my questions are answered and time is taken by my doctor to explain dystonia and its management."

## Satisfaction with Health and Dystonia Management

Almost half (48.7%) of all survey respondents indicated that they were satisfied with their overall health and the degree of management of their dystonia. When considered on a disease-state basis, patients living with segmental dystonia, generalized dystonia and cervical dystonia are slightly more satisfied with the management of their dystonia than patients in other groups.

Patients under the care of neurologists, physiatrists or movement disorders specialists were more satisfied with their overall health status and dystonia management than those under the care of an otolaryngologist or ophthalmologist.



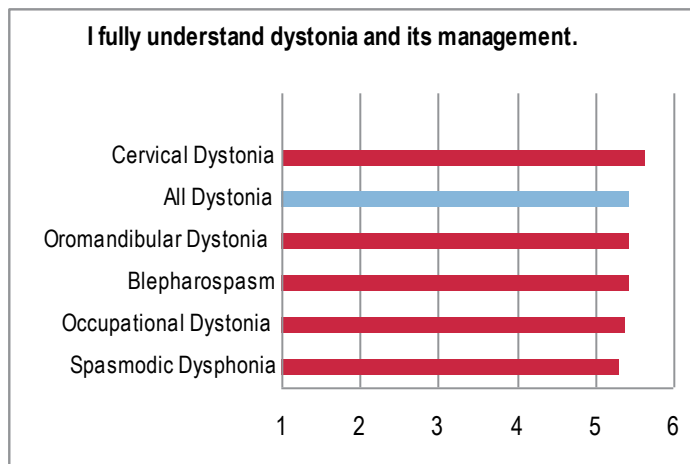
Please indicate how strongly you agree with the statement: **I believe that my symptoms from dystonia are well managed and I am satisfied with my overall health right now.**

## Understanding of Dystonia

Dystonia patients demonstrated a high degree of confidence when asked to self-assess their level of understanding regarding dystonia and its management. Almost 84% of respondents indicated some degree of agreement with the statement (Strongly agree [21.1%], Agree [34.8%] and Somewhat Agree [28%]). Approximately 10% of respondents indicated some degree of dissatisfaction with the management of their dystonia (Slightly disagree [4.3%], Disagree [4.6%], Strongly disagree [1.7%]). Approximately five percent of respondents were ambivalent (neither agree nor disagree).

When considered on a disease-state basis, patients living with cervical dystonia self-reported a higher degree of understanding of dystonia and its management than patients living with other types of dystonia.

In general, the type of physician that cares for these patients did not impact the degree of patient confidence in their dystonia knowledge.



Please indicate how strongly you agree with the statement: **I fully understand dystonia and its management.**

WE MOVE invites you to explore the  
Movement Disorder Virtual University  
at **www.mdvu.org** —*your source for movement  
disorder information and educational activities*

FOR HEALTHCARE  
PROFESSIONALS

MDVU offers the busy professional:

- Information on adult and pediatric movement disorders
- E-MOVE: Cutting-edge electronic news service reporting on emerging clinical advances and therapeutic approaches
- Interactive learning modules and online CME activities
- Thought-provoking case studies with pre-treatment and post-treatment video
- Office tools, including rating scales, dosing guidelines, and more
- Teaching materials such as slide sets with footnoted narratives
- Opportunities for peer interaction in proprietary chat rooms

MDVU is brought to you by WE MOVE at [www.wemove.org](http://www.wemove.org), a not-for-profit organization that has been educating and informing the movement disorder community for more than a decade. WE MOVE believes that increased knowledge and understanding promote timely, accurate diagnosis and up-to-date treatment, resulting in a better quality of life for individuals affected by movement disorders.

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