

# Impact of Tardive Dyskinesia (TD) on Patients and Caregivers

Authors: Rakesh Jain, MD, MPH; Rajeev Ayyagari, PhD; Debbie Goldschmidt, PhD;  
Mo Zhou, PhD; Stacy Finkbeiner, PhD; Sam Leo, PharmD

There has been little information about how TD affects the everyday lives of people living with it.  
A survey was conducted to look at how TD affects people who live with it and those who care for them<sup>1,2</sup>

Who took the survey

**269**  
people living  
with TD

**162**  
caregivers of people  
living with TD

The average age of people  
who answered the survey

**40.5**  
years old

**EVERYONE**

who took the survey was either living with TD **AND** schizophrenia, bipolar disorder, or major depressive disorder **OR** was an unpaid caregiver for a person living with TD and schizophrenia, bipolar disorder, and/or major depressive disorder

# PEOPLE LIVING WITH TD<sup>1</sup>

# CAREGIVERS OF PEOPLE LIVING WITH TD<sup>2</sup>

## QUESTIONS ASKED

How does TD affect **physical activities** that you do every day, such as getting dressed, eating, sleeping, and talking?

How do you feel **emotionally** about living with TD?

How has living with TD changed your **social activities**?

How do **family, friends, acquaintances, and strangers act** towards your TD? How does that make you feel?

How does TD change the way you **work**?



## QUESTIONS ASKED

What **kind of assistance do you give** to the person with TD?

Which caregiving task is **most burdensome**?

How do you feel **emotionally** about caregiving?

How has their TD impacted **your everyday activities and social life**?

How has their TD **changed your work life**?

## PEOPLE LIVING WITH TD ANSWERS PROVIDED<sup>1</sup>

**More than half of people said that TD was quite a bit or very bothersome**

### PHYSICAL ACTIVITY

- More than **9 out of 10** people reported that **TD affects how their body functions**
- More than **3 out of 4** people reported moderate or severe impact on things like being able to **fall and stay asleep, exercise, do household chores, hold things, and eat**

### EMOTIONS

- More than **3 out of 4** people said they sometimes, often, or always feel **sad/unhappy, angry, tired, anxious, unable to focus, unmotivated**, and more because of TD

### SOCIAL LIFE

- More than **3 out of 4** people said that TD sometimes, often, or always **affected whether they were able to enjoy fun things, do social activities, socialize with friends & family, and appear on video**
- More than **6 out of 10** people were bothered by **negative reactions** by others, such as **staring, asking what was wrong, making jokes, and grabbing them to stop them from moving**

### WORK LIFE

- At least **1 out of 3** people said that TD **stopped them from applying for a job, applying for a promotion, or getting a job**

## WHAT WERE THE RESULTS?



## CAREGIVER ANSWERS PROVIDED<sup>2</sup>

**Showering/bathing was the task caregivers said was most burdensome**

### CAREGIVER PHYSICAL ACTIVITY

Nearly **3 out of 4** caregivers reported helping people with TD with a variety of tasks, including **grocery shopping, managing medication, household chores, making meals, and driving**

### CAREGIVER EMOTIONAL HEALTH

More than **1 out of 5** caregivers said they feel **anxious or worried, sad or unhappy, overwhelmed, overburdened, and stressed or strained** because of caring for a person with TD

### CAREGIVER SOCIAL LIFE AND ACTIVITIES

- About **3 out of 10** caregivers said the person's TD often or always impacted their ability to **enjoy the things they do for fun, join social activities, and date or meet new people**
- **Nearly half** of caregivers said regular activities like **housework, shopping, and exercise** were impacted by their caregiving activities

### CAREGIVER WORK LIFE

- Caregivers who had jobs reported **missing work 13.8%** of the time
- They also reported that caregiving duties **affected their focus and productivity by 44%**

**TD is a significant burden on people's physical activity, emotions, social life, and work life<sup>1</sup>**

**TD has a significant burden on caregivers of those living with TD<sup>2</sup>**

# STUDY CONCLUSION

## What was the survey's impact?<sup>1,2</sup>

- This was one of the largest surveys ever done for TD
- This was the first survey to understand the experience of caregivers for people with TD
- The results show that managing TD may help people living with TD and their caregivers improve their emotional well-being, social life, and productivity

## What happens next?

- Healthcare workers, people living with TD, and their caregivers can use this information to guide discussions about the ways that TD affects each individual



Scan the QR code to view the patient publication



Scan the QR code to view the caregiver publication

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**References:** **1.** Jain R, Ayyagari R, Goldschmidt D, Zhou M, Finkbeiner S, Leo S. Impact of Tardive Dyskinesia on Physical, Psychological, Social, and Professional Domains of Patient Lives: A Survey of Patients in the United States. *J Clin Psychiatry*. 2023;84(3):22m14694. Published 2023 Apr 3. doi:10.4088/JCP.22m14694 **2.** Jain R, Ayyagari R, Goldschmidt D, Zhou M, Finkbeiner S, Leo S. Impact of tardive dyskinesia on patients and caregivers: a survey of caregivers in the United States. *J Patient Rep Outcomes*. 2023;7(1):122. Published 2023 Nov 28. doi:10.1186/s41687-023-00658-9