

Living Your Best Life With Tardive Dyskinesia

Speakers



Sherland Peterson

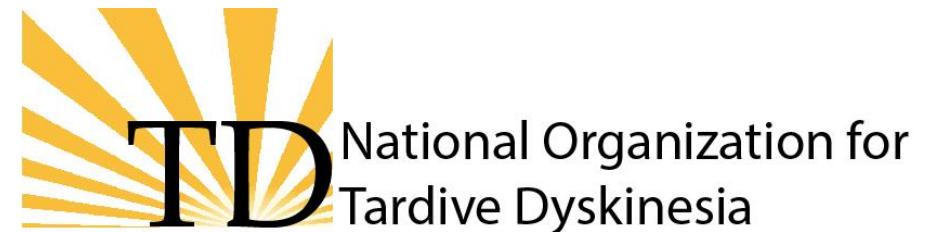
Lived Experience

Bill Cote

Senior Director
National Organization for
Tardive Dyskinesia

Living your best life with TD

Improving quality of life and
accessing helpful resources



Bill Cote
Senior Director

Impact of TD


- Latest estimate: **750,000** people suffer from some form of TD
- Only 20-30% of people with TD have been diagnosed
- Over 75% of people with TD said it has a “severe impact” on physical, psychological, and social well-being





Impact on Quality of Life


TD can affect most aspects of daily life:

- Career pursuits
 - Personal relationships
 - Dating/Social life
 - Hobbies and interests
 - Emotional outlook/self-esteem
 - Activities of daily living
- 



Impact on Quality of Life

Latest TD Survey says...

- >75% feel embarrassed or self-conscious
 - >40% feel ability to socialize affected
 - 46% say ability to work impacted
 - 53% ability to sleep impacted
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Impact on Quality of Life

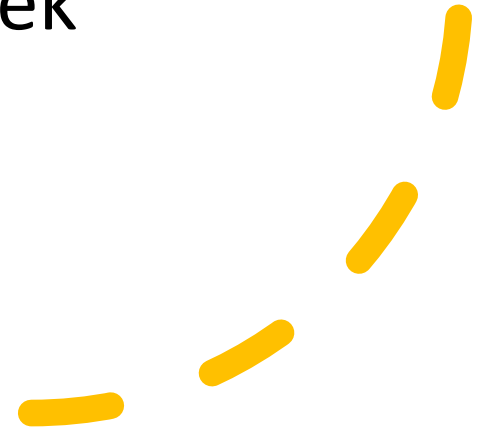
- Almost 50% experience moderate to severe anxiety or depression
- 32% eating is impacted
- 29% impacts self-care



Manifestations of TD

TD can cause:

- Sores in the mouth
- Speech impairment or involuntary grunting
- Biting lip, tongue and cheek
- Dental damage



Manifestations of TD

TD frequently causes:


- Difficulty chewing/swallowing/drinking
- Gait/balance issues
- Breathing complications ("Respiratory Dyskinesia")
- Muscle pain/discomfort
- Cognition/thinking issues



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Patient
Resources:
TDhelp.org

National Organization for Tardive Dyskinesia (NOTD)

- The only 501(c)(3) in the U.S. dedicated to supporting those with TD
 - NOTD raises awareness, provides education, patient support and advocacy
 - Visit NOTD at www.TDhelp.org
- 
- A decorative graphic consisting of several short, thick yellow dashes arranged in a curved, upward-sloping path in the bottom right corner of the slide.

**Patient
resources:
TDhelp.org**

Need TD Resources?

- **Visit www.TDhelp.org**
 - Join a virtual TD support group or caregiver support group
 - Learn about our TD Symptom Tracker app
 - View educational webinars and videos
 - Locate a movement disorders specialist
 - Learn about TD treatments

TD Risk Factors

Risk factors for TD:

- Being an older adult (50+)
- Female (especially post-menopausal)
- White or of African descent
- A member of your immediate family has TD
- Having a behavioral health condition such as bipolar, schizophrenia, schizoaffective disorder
- Having experienced traumatic brain injury

TD Risk Factors

Risk factors for TD (continued):

- Having diabetes or HIV
- History of alcohol or substance use, especially stimulants
- Being a smoker
- Having experienced early onset extrapyramidal symptoms (EPS) such as dystonia, pseudo-parkinsonism and akathisia

TD Risk Factors


Risk factors for TD (continued):

- Having taken lithium prior to a TD-causation medicine
- Being a slow or very fast metabolizer of drugs metabolized by the CYP2D6 enzyme



Signs/What to watch for...

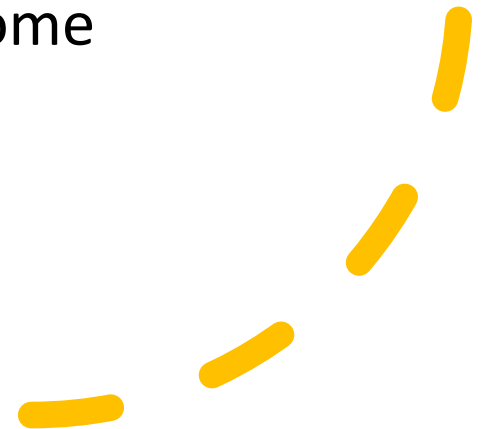
Watch for any unusual involuntary movements:

- Mild to severe twitching
 - Strange movements of the tongue
 - Rubbing together of lips
 - Grimacing of the face
- 

Signs/What to watch for...

Additional movements to watch out for:

- Fast blinking of the eyes
- Shaking or jerking in the hands, feet, or torso
- Unusual tapping of the fingers or toes
- Thrusting of the pelvis
- Burning pain in the mouth or genitals referred to as tardive pain/sensory syndrome



How to talk about TD...

If you notice friend/loved one starting to exhibit movements:

- Discuss privately (sensitive subject)
- Realize the person with TD may not know they are making these movements
- Let them know that some medications can cause these movements
- Advise them to talk to their doctor immediately

Screening for TD

You should be frequently screened for TD by your doctor:

- If you are at high risk, get screened **at every visit**
- If at lower risk, get screened every six months
- **Don't stop taking your meds or adjust your dose without consulting your doctor!**

TD Treatments

Evidence-based treatment options

- valbenazine (Ingrezza[®])
- deutetrabenazine (Austedo[®])
- clonazepam (Klonopin, a benzodiazepine)
- Ginkgo Biloba (primarily for TD caused by 1st generation antipsychotic)
- amantadine (esp. for mixed TD/Parkinsonism)
- gabapentin (primarily for RD)

TD Treatments

Evidence-based treatment options (cont'd)

- Botox (caution: Botox can relax throat muscles too much and make swallowing more difficult)².
- Branched-chain amino acids (depletes dopamine precursors in brain)
- Vitamin E and C
- Yi-gan San (Japanese herbal compound)
- Deep brain stimulation

(Visit TDhelp.org/treatments for more info)

Dopamine and TD

TD treatments can cause low dopamine levels -- symptoms:

- Hand tremors or other tremors at rest, loss of balance or coordination, increased muscle/limb stiffness, muscle cramps (symptoms of drug-induced parkinsonism)
- Restless legs syndrome
- Tired
- Depressed; you feel hopeless



Dopamine and TD

Other symptoms of low dopamine:

- Problems with short-term memory, managing daily tasks and solving simple thinking problems
- Anger, low self-esteem, anxiety, forgetfulness, impulsiveness and lack of organizational skill (symptoms of ADHD)
- Social withdrawal, reduced emotions, don't feel pleasure
- Gastrointestinal symptoms, including chronic constipation
- Low sex drive



Supplements that may help TD

Supplements that can help those with TD:

- Magnesium L-threonate* (for brain health) or magnesium glycinate (for muscle pain/tightness)
- Melatonin
- Omega 3s, especially DHA
- Grapeseed Extract (anecdotal evidence: reduces movements)
- Bacopa (Indian herb – can reduce dopamine; may interact with Ingrezza or Austedo)
- Caution with manganese – 11mg max dose for adults

* Some people may find this to be too stimulating

TD Triggers and Helpful Hints

Avoid these TD triggers:

- Avoid caffeinated drinks (coffee/soda)
- Avoid aspartame (NutraSweet[®], Equal[®]) in diet/sugar-free foods
- Reduce stress
 - Vagus nerve stimulators help reduce anxiety
- Get enough sleep



TD Triggers and Helpful Hints

- Be careful with tyrosine (dopamine precursor), especially in energy drinks
- Be careful of meds and supplements that are stimulants (e.g., Adderrall[®])
- Don't miss a dose of your medication, especially if you're trying to wean off it



Anticholinergic drugs

Anticholinergic drugs can exacerbate TD

Symptoms of too little acetylcholine are often caused by anticholinergic drugs which decrease or block action of the **parasympathetic nervous system receptors**.

Commonly prescribed anticholinergic for TD:

- benztropine (Cogentin®)
 - This drug can treat movements from Parkinson's disease; but **it usually makes TD movements worse!**

Anticholinergics

Many people are on numerous anticholinergics and don't realize it.


(Cognition is poor, lack of REM sleep, constipation, dry eyes and skin, pupils don't constrict properly, etc.)





Hope on the Horizon


What's on the horizon for TD?

- A new antipsychotic that doesn't affect dopamine is currently in Phase 3 trials.
 - Precision medicine promises to identify genetic predispositions to TD
- 



Hope on the Horizon

What's on the horizon for TD?

- Research into using VMAT2 inhibitors as adjunct to antipsychotics before movements start – may allow lower dose of antipsychotic
- 



For questions
or support

Questions?

Email us at info@tdhelp.org

Phone: 866-TDHELP1



Help us help
those with TD

To help us continue our mission of raising awareness, education, patient support and advocacy, please donate at **www.TDhelp.org**

