

# Tardive Dyskinesia (TD) A Quick Guide for Caregivers

## WHAT IS TD?

A movement condition from long-term psychiatric medications causing involuntary, repetitive movements in the face, mouth, or body.

EARLY SIGNS TO WATCH	WHAT INCREASES RISK	WHAT YOU CAN DO
<p><i>Small, repeated movements, including:</i></p> <ul style="list-style-type: none"> <li>Lip smacking</li> <li>Grimacing</li> <li>Finger tapping</li> <li>Tongue moving</li> <li>Rapid blinking</li> <li>Body rocking</li> </ul> <p><i>May come and go; worsen with stress or fatigue</i></p>	<p><b>Long-term antipsychotic use</b> Most common trigger</p> <p><b>Older (1st-gen) medications</b> Higher-risk profile</p> <p><b>Higher doses + longer treatment</b> Risk grows over time</p> <p><i>TD can appear months or years after starting or stopping medication.</i></p>	<p><b>TRACK</b> Document movements, medication changes, side effects</p> <p><b>SPEAK UP</b> Tell the doctor what you see. Ask: Could this be TD?</p> <p><b>ASK ABOUT OPTIONS</b> Safer meds? Adjust treatment? Treatments for TD?</p>

## CAREGIVER VOICES

“ The first thing I noticed was the lip smacking. I noticed the symptoms and thought it didn't look normal... After a while, we saw a doctor, and he diagnosed my uncle with TD.  
Tricia—caring for her uncle with a mood disorder

“ I noticed my husband making strange movements with his mouth, and they were getting progressively worse. So, I videotaped him on my phone and played it back to him.  
Diane—caring for her husband with bipolar II

“ She kept saying it was a twitch... We kept noticing repeated odd movements of her tongue. Because she was in denial, I reported the symptoms to the doctor.  
Richard—caring for his aunt with schizophrenia

## KEY RESOURCES

Caregiver Action Network [caregiveraction.org/understanding-tardive-dyskinesia](https://caregiveraction.org/understanding-tardive-dyskinesia)

Patient Advocate Foundation [patientadvocate.org](https://patientadvocate.org)

National Alliance on Mental Illness (NAMI) [nami.org](https://nami.org)

Movement Disorder Policy Coalition [movementdisorderspolicy.org](https://movementdisorderspolicy.org)

Depression and Bipolar Support Alliance [dbsalliance.org](https://dbsalliance.org)

Treatment Advocacy Center [treatmentadvocacycenter.org](https://treatmentadvocacycenter.org)

Dystonia Medical Research Foundation [dystonia-foundation.org](https://dystonia-foundation.org)

# Navigating Care for Your Loved One with TD

Practical tools and support for caregivers

NAVIGATING CARE	UNDERSTANDING BARRIERS	IN SUMMARY
<p><b>KNOW YOUR ROLE (WITH HIPAA)</b></p>	<p><b>COMMON BARRIERS</b></p>	<p><b>REMEMBER</b></p>
<p><b>Your voice still matters in your loved one's care.</b></p> <p><b>You can always:</b></p> <ul style="list-style-type: none"> <li>• Share concerns and observations</li> <li>• Provide updates to the care team</li> <li>• Request permission forms to stay involved</li> </ul>	<p><b>Denial</b> Your loved one may not believe they have TD.</p>	<p><b>TD is treatable</b> There are FDA-approved treatments for TD. Treatment can significantly reduce symptoms.</p>
<p><b>Talking to the Doctor</b> You have the right to share what you observe.</p> <p><i>Say: "I noticed repetitive movements. Could this be TD?"</i></p>	<p><b>Fear</b> Worried medication changes could cause relapse.</p>	<p><b>You are not alone</b> Thousands of caregivers support someone with TD. Communities and resources exist.</p>
<p><b>Getting a Diagnosis</b></p> <ul style="list-style-type: none"> <li>• Ask for an AIMS test (abnormal movement scale)</li> <li>• Request a movement disorder specialist</li> <li>• Bring video evidence to the appointment</li> </ul>	<p><b>Lack of awareness</b> Many providers miss TD symptoms.</p>	<p><b>Your notes are clinical data</b> Write down what you see: when, how often, which body parts.</p>
<p><b>IF TREATMENT IS DENIED BY INSURANCE</b></p>	<p><b>Stigma</b> Reluctance to draw attention to movements.</p>	<p><b>A second opinion is always an option</b> If your doctor dismisses the movements, seek another provider. <i>What you notice, track, and say can truly change outcomes.</i></p>
<ul style="list-style-type: none"> <li>• Ask for the reason in writing</li> <li>• Request an appeal with medical support</li> <li>• Look into patient assistance programs</li> </ul> <p><i>A denial is often a step—not the end.</i></p>	<p><i>Persistent advocacy can make the difference.</i></p>	
	<p><b>BARRIERS ARE REAL</b></p>	
	<p><b>Cost of medications</b> High-cost drugs may require prior auth, appeals, or patient assistance programs.</p>	
	<p><b>Limited specialist access</b> Movement disorder specialists can be hard to find—telehealth may help.</p>	
	<p><b>Stigma</b> Social stigma around mental illness and TD affects both patients and families.</p>	

## TAKE CARE OF YOURSELF!

*Caregiving is demanding. You deserve support.*

*"We were celebrating my brother's birthday and invited some friends over. When they saw my mom, always moving her mouth, her tongue sticking out, and blinking her eyes, I got some weird comments. 'Why is your mom always chewing?' I tried to explain to them that my mom was diagnosed with TD. Some people were able to understand, but some weren't."*

**Jessica—caring for her mom with bipolar disorder**

- Give yourself permission to feel frustrated or sad
- Set small, manageable goals each day
- Accept help, you cannot do this alone
- Reach out: caregiver support groups help

*"We have not experienced any external comments or feelings of my son being stigmatized because of his situation and his illness. However, I must admit that I had to work on my own sense of shame regarding his situation. I'm not sure if I was going out of my way to protect him from others, but I think it was also part of protecting myself from people looking at him and making comments."*

**Irene—caring for her son with schizophrenia**

**Caregiver Action Network**  
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