

Guide to living with

Health**monitor**[®]

Tardive Dyskinesia

- Experiencing movements you can't control?
- Lips, tongue, jaw, limbs, toes or fingers affected?
- Have you taken an antipsychotic medication?

It could be tardive dyskinesia

See p. 11

"TD doesn't control me anymore!"

Thanks to the right medication and expert care, Phyllis Hall found life-changing relief. Now she wants others to know *there is hope!*

COMPLIMENTS OF YOUR HEALTHCARE PROVIDER

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Guide to living with Tardive Dyskinesia



8 Because of tardive dyskinesia, Phyllis once needed a cane to walk. Now, thanks to the right treatment, she has no problem keeping up with her pup, Roxy!

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You *can* take control of TD!

Today's advanced treatments for tardive dyskinesia mean you don't have to put limits on your life. —BY AMANDA PROST

It was a simple question that ended up having big consequences for Jane M. “My sister and I were eating lunch at a restaurant, and out of the blue, she asked if I needed chapstick,” recalls the 59-year-old from Seattle. “She said I kept licking and pursing my lips so she thought they may be dry, but I could tell by the look of concern on her face that something more was going on.”

Indeed, Jane had noticed that something odd was happening with her lips but hadn't realized just how noticeable it was to others. It was like a tic that she couldn't control—and it left her feeling exceptionally self-conscious. “The stares from strangers were the worst, and eventually I even started to find excuses to avoid going out with friends,” she says. “I didn't know how to explain what was wrong, and it seemed so bizarre that, in many ways, I wanted to pretend it wasn't happening.”

But the involuntary movements just seemed to get more frequent, and eventually, she decided to see her doctor. After a series of tests and scans ruled out several potential causes, she had a diagnosis: tardive dyskinesia (TD). Her doctor explained it was related

to the medication she was taking for bipolar disorder—basically, it was a side effect that resulted in uncontrollable movements that could occur in different parts of the body.

“It was a bit of shock to be honest—I'd been on the same prescription for almost 10 years, and it was working well with no problems,” she says.

After discussing treatment options with her doctor, they decided the best course of action was to keep her on the same drug for her bipolar disorder and add another medication to her daily regimen, one specifically designed to ease TD symptoms.

“Within about six weeks, my lip pursing and licking practically went away,” Jane says. “But what I gained is so much more: My confidence is back. I can enjoy my time with friends and family. I don't feel like I have to hide away at home. It's given me my life back!”

If you are experiencing TD symptoms, you, too, can take control of your condition by working with your doctors to find the treatment that's right for you. Start with this guide to learn more about TD and how you can find relief.

What is TD?

Tardive dyskinesia is a movement disorder characterized by involuntary movements of the face and body. It may develop in people taking certain antipsychotic medications (also called neuroleptic drugs) for schizophrenia, bipolar disorder and other mental illnesses. (While less common, TD also may result from certain drugs used to treat other health problems, including upset stomach, nausea and vomiting.)

Researchers believe antipsychotics are a major culprit because they

work by blocking a brain chemical called dopamine. In addition to playing a role in mood and emotion, dopamine also helps cells communicate so muscles can perform smoothly. When levels of dopamine drop too low, doctors say it may give rise to TD's unusual movements.

The term “tardive” means delayed, and “dyskinesia” means abnormal movement. It's called tardive because symptoms do not develop immediately when patients begin taking medications, but rather

occur anywhere from three months to years later. In some cases, TD symptoms may start even after a medication has been stopped.

Who is at risk?

An estimated 500,000 people in the United States have TD. And research shows about 30% of people taking antipsychotic medications will develop symptoms at some point.

There are no blood tests or scans that can confirm diagnosis. Instead, physicians work to rule out

other causes and use the Abnormal Involuntary Movement Scale (AIMS) to evaluate symptoms and grade the level of involuntary movements.

TD occurs more frequently in people taking first-generation antipsychotics such as haloperidol, fluphenazine, perphenazine and chlorpromazine, but still may affect those on second-generation antipsychotics such as aripiprazole, risperidone, quetiapine and paliperidone. And the longer a person takes a medication, the greater the chance of developing TD. ▶

DID YOU KNOW?

About 500,000 people in the U.S. have TD.



While TD can occur in anyone, certain factors are correlated with an increased risk:

- Being older than 50
- Being female, especially postmenopausal
- Having diabetes
- Being African American or Asian American
- Having alcohol or substance abuse issues
- Having mental illness (e.g., schizophrenia, psychotic disorder, mood disorder)

What are the symptoms?

TD manifests differently from person to person. Symptoms can be mild, moderate or severe, with about 60% to 70% of cases deemed mild, and they may appear only in one region of the body or occur in several areas. Many patients aren't even aware of their involuntary movements.

Orofacial or oro-bucco-lingual dyskinesia affects the face, primarily the lips, jaw or tongue. Symptoms include:

- Excessive eye blinking or squinting
- Lip smacking, pursing or puckering
- Protruding or writhing tongue
- Chewing, clenching, chomping or laterally moving the jaw
- Grimacing or frowning

Dyskinesia may also affect the torso, arms, legs, fingers and toes. Symptoms include:

- Wiggling fingers
- Tapping feet
- Ankle twisting
- Shifting or hyperextending the torso
- Swaying from side to side

How is TD treated?

It's important to alert your doctor if you experience movement problems,

as early intervention may be able to reverse TD. Continue taking your regular medication as prescribed until you and your physician come up with a personalized treatment plan, which will depend on a variety of factors, including the severity of your symptoms and how long you've been taking your medication. One first step may be to lower the dosage of your current meds. Other options include:

Switching to a newer antipsychotic.

If you're taking a first-generation neuroleptic, your doctor may consider changing your prescription to a second-generation medication, which is less likely to cause TD. Studies show that 30% of people on first-generation meds experience TD, while 21% of those on second-generation antipsychotics who had previously been on a first-generation drug have symptoms.

Adding a drug that eases TD symptoms.

In 2017, the FDA approved new medications to treat TD. They help by regulating the amount of dopamine in the specific brain regions that control movement. They are taken once a day along with your regular medication. It's important to note that they don't affect the way your antipsychotics work.

Your healthcare provider may also recommend you take over-the-counter supplements that can help support brain function. These include vitamins E and B6, as well as ginkgo biloba.

And for severe symptoms, deep brain stimulation may be an option. This procedure involves implanting electrodes in specific areas of the brain. The electrodes release electrical impulses that help regulate neurotransmitters. 🧠

Meet your healthcare team

Partnering with many of these healthcare professionals will ensure the right management plan tailored to your TD symptoms and treatment goals:

Primary care provider: This doctor can address a number of health-related concerns and will help coordinate your care with referrals to the appropriate specialists.

Neurologist: Specializing in disorders of the brain and the nervous system, this physician helps diagnose TD and works to develop a treatment plan and manage symptoms.

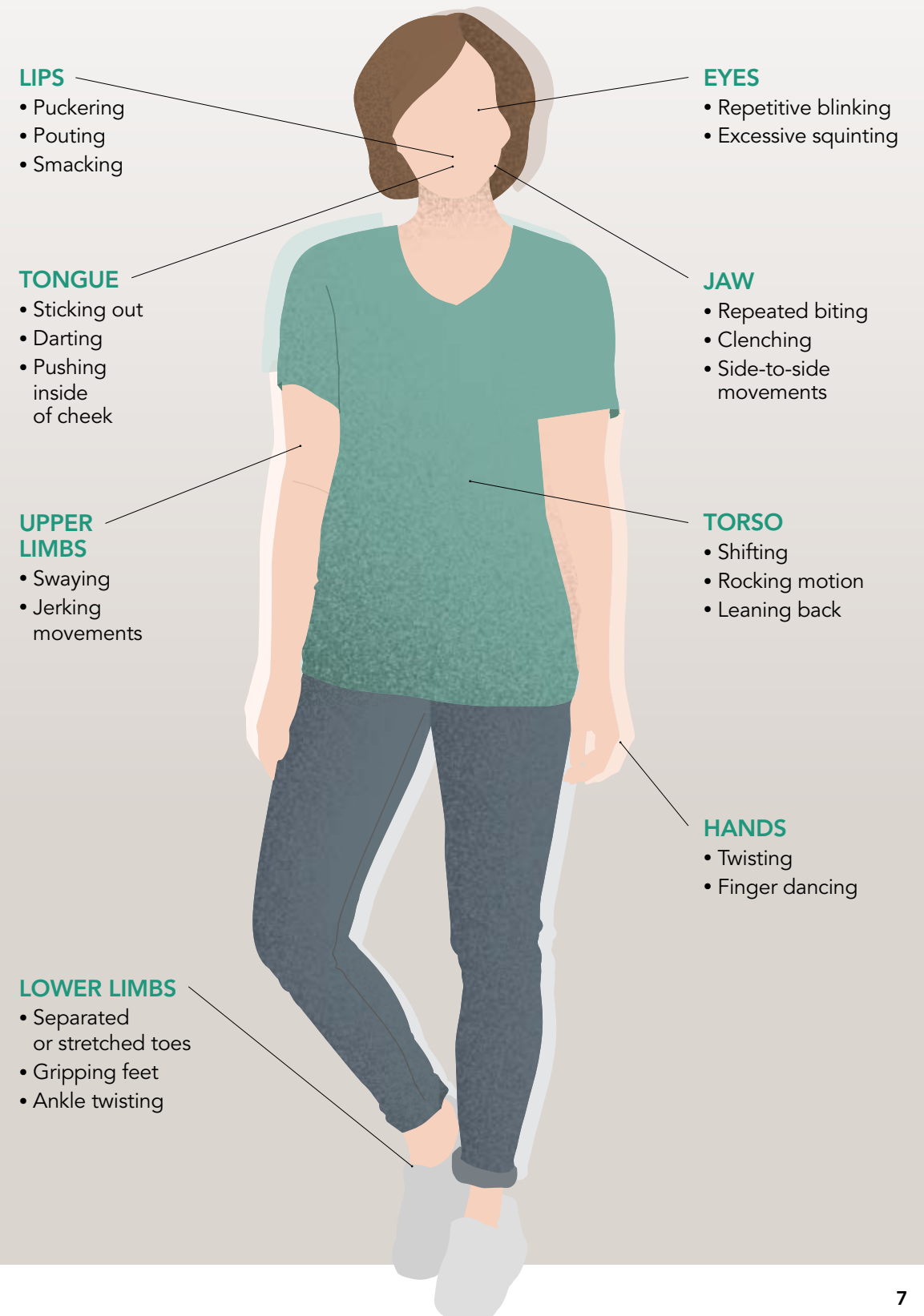
Movement disorder specialist: This is a neurologist who's received additional specialized training in movement disorders like TD and can further help treat symptoms.

Psychiatrist: This doctor has specialized training in mental health disorders and can help manage any antipsychotic or antidepressant medications you may be taking, along with their dosing.

Physical therapist: A PT can work with you to create an exercise plan to improve balance and coordination, helping to bolster posture as well as prevent falls.

TD affects everyone differently

Here are the ways TD movements can appear.



“My TD symptoms are gone!”

Thanks to the right treatment—and never giving up hope—Phyllis got relief from her uncontrollable movements. Today, she’s thrilled to have a new outlook on life! — BY BETH SHAPOURI

Phyllis Hall has achieved her wildest dreams. Once afflicted with a case of tardive dyskinesia (TD) so severe she dropped 50 pounds just from the constant uncontrollable muscle movements, she is now in remission and completely twitch-free. The LaMarque, TX, resident wondered if that was even possible when she was first diagnosed with TD back in 2014 after full-body spasms landed her in the ER.

“A doctor walked by me and I swear he did the Moonwalk back and looked straight at me and said, ‘You *have* heard of tardive dyskinesia, right?’” recalls Phyllis. “Heard of it? I couldn’t even pronounce it!”

“I looked for help”

After struggling with the symptoms for three years, Phyllis was relieved at having a diagnosis—and determined to learn all she could about dealing with the condition. After a neurologist identified a medication she was taking as the root cause of her TD and advised her to stop taking it, Phyllis quit the drug cold turkey. She landed in the hospital for a week. And while she was there, the bad news piled up: Her husband, who had been battling cancer, took a turn for the worse.

The couple thought it was a sign for both of them. “I wasn’t getting any better; he was terminal. We decided we were going to be buried together,” she says. (Sadly, her husband passed away in 2015,

leaving Phyllis feeling more alone than ever in her struggle.)

“Everything took a positive turn!”

In the years following her diagnosis, Phyllis’ TD took an ever-stronger hold of her body. The jerking and twisting movements worsened to the point where she needed a cane to walk and her weight dropped to just 91 pounds. She tried to stay positive, she says, but it was difficult. “I did lose hope a few times,” she admits.

Unexpectedly in 2017, Phyllis’ hopes were rekindled. That’s when her doctor prescribed a newly approved medication for adults with TD. Slowly, things began to improve, and the number and frequency of her involuntary movements dwindled. One moment from her recovery that particularly stands out: “My roommate remarked, ‘Phyllis you left your cane in the bathroom!’” Phyllis hadn’t even noticed she no longer needed it to walk.

“Now, I’m planning my future!”

These days, Phyllis’ symptoms are completely gone. After so many years of being sidelined by TD, she is hopeful about her future, with plans to go back to beauty school and return to the hairstyling career she left behind 17 years ago. “I feel like Wonder Woman,” says Phyllis. “I have goals, dreams and a new lust for life. This year is a new start!”

See Phyllis’ tips on p. 10. ▶



“I have goals, dreams and a new lust for life,” says Phyllis.

“With TD, it helps to soothe away the stress”

Here, Phyllis shares a few of the strategies that help her live well despite TD:



Zen out
Phyllis Hall of LaMarque, TX, had a severe case of TD that caused her to lose 50 pounds from her constant movements. But with a combo of the right medication and lifestyle changes, Phyllis sent her TD into remission. At the height of her TD, Phyllis meditated three times a day; these days, she does it for a few minutes before bed. Not sure where to start? Try a guided meditation app like Calm (calm.com) or Headspace (headspace.com).

Connect with your dentist
As with many people who have TD, habitual mouth movements have taken a toll on Phyllis’ teeth. Her advice: Talk to your dentist about using a mouthguard if you’re gnashing your teeth. “I wish that someone would have told me to use one sooner.”

Try a soak
For pain relief, Phyllis squeezes in some tub time. “I take baths with Epsom salt and lavender,” she says. Adding the two soothers to

her bath water relaxes her muscles and eases discomfort, she adds. On the days she wants a tingling boost, she adds fresh mint!

Unwind to music
When Phyllis feels like life is becoming stressful, which can make dealing with TD even more challenging, she turns to music, often selecting either mellow classical or jazz. Her latest find: meditation music on YouTube! She finds the word-free tunes create a calming ambience. 🎧

Report your symptoms

Managing tardive dyskinesia (TD) can be challenging, but by sharing the details of your uncontrolled movements with your doctor, you’re one step closer to getting relief. Fill out this worksheet and review it with your doctor at your next appointment to help ensure you get the best treatment for you.



1. Check only the boxes that apply to you if you...

| | Many times per minute | Many times per hour | Many times per day | Doesn't apply |
|---------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| Stick out your tongue | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Blink your eyes rapidly | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Make chewing motions | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Smack or pucker your lips | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Puff out your cheeks | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Frown or grimace | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Grunt | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Wiggle your fingers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Tap your feet | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Flap your arms | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Stick out your pelvis | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Sway from side to side | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Other: | _____ | | | |

2. My uncontrolled movements began (please indicate when):

3. Who noticed your uncontrolled movements first?

me friend or loved one coworker stranger

other: _____

4. List all the medications you currently take or have taken within the last two years.

(include prescription medication, over-the-counter medicines and supplements):

How does TD affect your life?

Take a moment to reflect on the ways your uncontrolled movements are impacting you. Then check the response that applies to you and fill in the sentences below. Review with your care team.



| Coping with my TD and its treatment... | Rarely | Occasionally | Often | Almost always |
|--|--------|--------------|-------|---------------|
| Causes me to limit my activities | | | | |
| Takes a toll on my mood | | | | |
| Makes working difficult | | | | |
| Puts a strain on my relationships | | | | |
| Makes walking difficult | | | | |
| Makes physical activity difficult | | | | |
| Saps my ability to enjoy life | | | | |
| Makes sleeping difficult | | | | |
| Makes me feel ashamed or embarrassed | | | | |
| Makes me angry | | | | |
| Makes me self-conscious | | | | |
| Causes me to isolate myself | | | | |
| Right now, TD is a big problem and disrupts my life almost every day. [] agree [] disagree | | | | |
| It's important for me to be able to _____ despite having TD. | | | | |
| I wish I could snap my fingers and _____ again. | | | | |
| On a scale from 1 (low) to 10 (high), my sense of hope is _____. | | | | |

Are you ready to do something about your uncontrollable movements caused by tardive dyskinesia (TD)?



If TD is impacting you, ask about INGREZZA® (valbenazine) capsules, the only once-daily treatment for adults with TD.



Talk to your psychiatrist to see if INGREZZA is right for you. Learn more at INGREZZA.com/Impact



Important Information

Approved Use
INGREZZA® (valbenazine) capsules is a prescription medicine used to treat adults with movements in the face, tongue, or other body parts that cannot be controlled (tardive dyskinesia). It is not known if INGREZZA is safe and effective in children.

IMPORTANT SAFETY INFORMATION

Do not take INGREZZA if you:

- are allergic to valbenazine, or any of the ingredients in INGREZZA.

INGREZZA may cause serious side effects, including:

- Sleepiness (somnolence).** Do not drive, operate heavy machinery, or do other dangerous activities until you know how INGREZZA affects you.
- Heart rhythm problems (QT prolongation).** INGREZZA may cause a heart problem known as QT prolongation. Symptoms of QT prolongation may include fast, slow, or irregular heartbeat, shortness of breath, dizziness or lightheadedness.
- Parkinson-like symptoms.** Symptoms include shaking, body stiffness, trouble moving or walking, or keeping your balance.

Tell your healthcare provider right away if you have a change in your heartbeat (a fast or irregular heartbeat), or if you faint.

Before taking INGREZZA, tell your healthcare provider about all of your medical conditions including if you: have liver or heart problems, are pregnant or plan to become pregnant, or are breastfeeding or plan to breastfeed.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

The most common side effect of INGREZZA is sleepiness (somnolence). Other side effects include changes in balance (balance problems, dizziness) or an increased risk of falls, headache, feelings of restlessness, dry mouth, constipation, and blurred vision.

These are not all of the possible side effects of INGREZZA. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Please see the adjacent page for the Brief Summary of Prescribing Information and visit www.INGREZZA.com/PI for full Prescribing Information.



Summary of Information about
INGREZZA® (valbenazine) capsules
 (in grab' zah)

What is INGREZZA?

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 It is not known if INGREZZA is safe and effective in children.

Do not take INGREZZA if you:

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Before taking INGREZZA, tell your healthcare provider about all of your medical conditions including if you:

- have liver problems
- have heart disease that is not stable, have heart failure or recently had a heart attack
- have an irregular heart rhythm or heartbeat (QT prolongation, heart arrhythmia)
- are pregnant or plan to become pregnant. INGREZZA may harm your unborn baby.
- are breastfeeding or plan to breastfeed. It is not known if INGREZZA passes into your breast milk. Do not breastfeed during treatment with INGREZZA and for 5 days after the final dose. Talk to your healthcare provider about the best way to feed your baby during treatment with INGREZZA.

Tell your healthcare provider about all the medicines you take, including prescription and over-the-counter medicines, vitamins and herbal supplements.

Taking INGREZZA with certain other medicines may cause serious side effects. Do not start any new medicines while taking INGREZZA without talking to your healthcare provider first.

What are the possible side effects of INGREZZA?

INGREZZA may cause serious side effects, including:

- Blurred vision (soreness). Do not drive, operate heavy machinery, or do other dangerous activities until you know how INGREZZA affects you.
- Heart rhythm problems (QT prolongation). INGREZZA may cause a heart problem known as QT prolongation. Symptoms of QT prolongation may include:
 - fast, slow, or irregular heartbeat
 - dizziness or fainting
 - shortness of breath
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- constipation
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- blurred vision

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The risk information provided here is not comprehensive. To learn more, talk about INGREZZA with your health care provider or pharmacist. The FDA-approved product labeling can be found at www.INGREZZA.com/PI or call 84-INGREZZA (844-847-3822).



Answers that make managing TD easier



include a medication specifically approved to treat TD.

STRESS AND TD

Q I've noticed my TD symptoms—wiggling my feet and “playing piano”—seem to get worse when I'm stressed, but there's not much I can do about my hectic life. Are stress and TD connected? If so, does that mean I just have to live with TD?

A Stress is a common aggravating factor for the involuntary movements of TD, and while you surely can't eliminate all tension from your life, you can include relaxation techniques in your everyday routine. Anything from listening to music or meditating to taking a walk or doing a crossword puzzle—whatever takes your mind off your stressors—may help. As for whether you have to live with TD, that depends: If the movements don't bother you, then you can choose not to treat it. But if you feel affected—physically, emotionally or socially—you may want to discuss with your doctor the use of a medication known as a VMAT2 inhibitor.

OUR EXPERT

Carlos Singer, MD, is a Professor of Neurology and Division Chief, Parkinson's Disease and Movement Disorders, Leonard M. Miller School of Medicine, University of Miami

IS TD TREATABLE?

Q My doctor wants me to stop the antipsychotic medication that's causing my TD. That terrifies me because in spite of the TD, my medication helps keep me stable. Is cutting out my drug the only way to get rid of the uncontrollable movements?

A It's understandable that you would be concerned about stopping a medication that's been helping you, TD aside. Fortunately, you have another option. The FDA has approved a type of drug called a VMAT2 inhibitor to treat TD, and it can be taken in addition to your antipsychotic medication. I'd suggest asking your doctor if you're a candidate.

OKAY TO SWITCH MEDS?

Q I'm on an antidepressant and have heard that, once you have TD (like I do), switching to a new antidepressant won't make it worse or make it better. Is that true?

A It depends on the kind of antidepressant that is being used or switched to. As long as neither the one you are using nor the one you are being switched to is an antipsychotic, your TD is not likely to change. If you are taking an antipsychotic that is being used as an antidepressant, switching to another type of antidepressant may make a difference, but this switch has to be carefully strategized with your doctor as it requires close monitoring of your TD and may

Let's talk about TD

You know something's wrong. You need help. Here's how to get it.



58%
Percentage of respondents in a recent survey who did not know that antipsychotic medications can cause TD.

Living with a disease like bipolar disorder and schizophrenia is hard enough. Adding a condition like tardive dyskinesia (TD)—marked by involuntary movements, such as lip smacking, arm flapping and foot tapping—can add to the challenge. Yet that's the reality for about 500,000 Americans affected by TD, which is largely caused by

the very medications people take to find relief from mental illnesses. It's a sad irony, of course, but today the outlook is brighter than ever, thanks to treatments that can effectively curb TD symptoms and make each day more manageable.

If you suspect you have TD, here's how to get the help you need—after all, why would you live with symptoms that undercut your

confidence and sap your joy when you don't have to?

Open up to your doctor.

If symptoms don't appear during your exam, your doctor won't know that TD may be a problem for you. That means it's up to you to get the conversation going. Try, "I've noticed movements that I can't control, like rocking and swaying. Could this

be related to the medications I'm taking to treat [fill in]?" Even easier: Fill out the worksheet on p. 11 and simply show it to your doctor. They will want to know the kinds of movements you're experiencing, how often they occur and how they affect your daily life. Consider that in a recent survey of people with TD, half said the condition made it hard to do their jobs, and two-thirds said their self-esteem and confidence took a hit.

Tip: Ask a loved one to video you while you're experiencing symptoms. It will help your doctor make a diagnosis of TD and assess its severity.

Ask for treatment—and make sure it works.

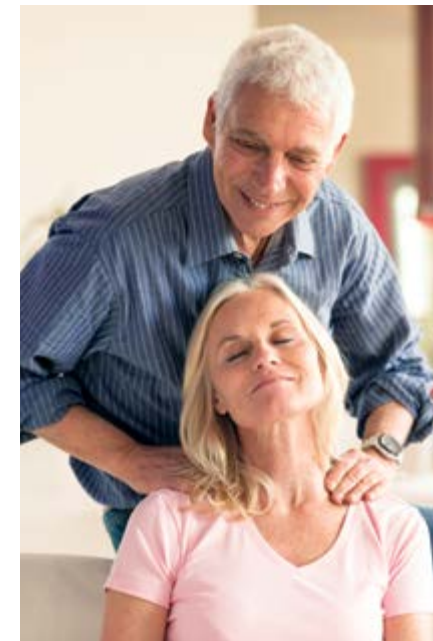
Together, you and your doctor will decide on a course of action. (See p. 6 to learn more about your treatment options.) Find out how long it might take for you to start seeing a decrease in your unwanted movements and monitor your progress. Some people find that treatment basically gets rid of their symptoms while others achieve near remission. At regular checkups

(usually every three to six months), your doctor may do an AIMS (Abnormal Involuntary Movement Scale) test, to assess the effectiveness of your treatment.

Don't forget: If your doctor adjusted the dosage of the medication that caused the TD, or if they switched your treatment, be sure to note how the change is affecting your mental health, as well as your TD symptoms.

Surround yourself with understanding.

Group support has been proven to increase confidence and boost one's sense of control, so ask your healthcare provider to recommend local resources for connecting with others who have TD. You can also visit Mental Health America, mhanational.org, or National Alliance on Mental Illness, nami.org, where you can find help locating in-person and online support groups, peer counseling and other resources. Don't forget to turn to close friends and loved ones, too. If they don't know much about TD, share this guide with them as a good first step.



Caregiver? Here's how you can be there!

Get educated. Learn all you can about TD, and if at times you feel frustrated or impatient, remember that your loved one has no control over their movements.

Keep an eye out. Your loved one may not realize that their TD movements are occurring or be unable to track their progress once treatment has started. Note symptoms, changes and trends and accompany them to their doctor's appointments so you can share important info.

Be compassionate. Your loved one may feel self-conscious or ashamed of their TD. Gently encourage them to continue with activities they enjoy and help them avoid isolating themselves. Explain TD to friends and family, so they can also be more understanding with your loved one.

“We’re thriving, even with TD!”

Receiving a diagnosis of tardive dyskinesia can feel overwhelming — but these warriors have found ways to thrive, and they’re sharing their tips for managing their symptoms along the way. —BY BETH SHAPOURI



PHOTOS BY EZEKIEL PHOTOGRAPHY

“Be kind to yourself”

Kathleen Shea

Connect with others who have TD

Last year, Kathleen Shea decided to seek out others in the TD community to feel less alone in her struggle with her symptoms—uncontrollable tongue movements and a burning sensation in her mouth. She was disappointed. “I couldn’t believe there was no organization [dedicated to TD] because I had read that 500,000 people have some form of tardive dyskinesia in the United States alone,” says the Spring Hill, FL, resident. So, she founded the National Organization for Tardive Dyskinesia (TDHelp.org), a nonprofit organization that provides information and support for people with TD. “Remember, you’re not alone on this journey,” Kathleen wants others with TD to know.

Stay social

Kathleen makes a point to get out to see friends and family when she’s feeling up to it. What she’s found: “It’s very hard not to socially isolate. The people who have families that support them and understand their tardive dyskinesia are the ones who seem to be coping the best.” Connecting with people, even just to get to church or hang with a buddy once a week, is vital, she says.

Avoid heat triggers

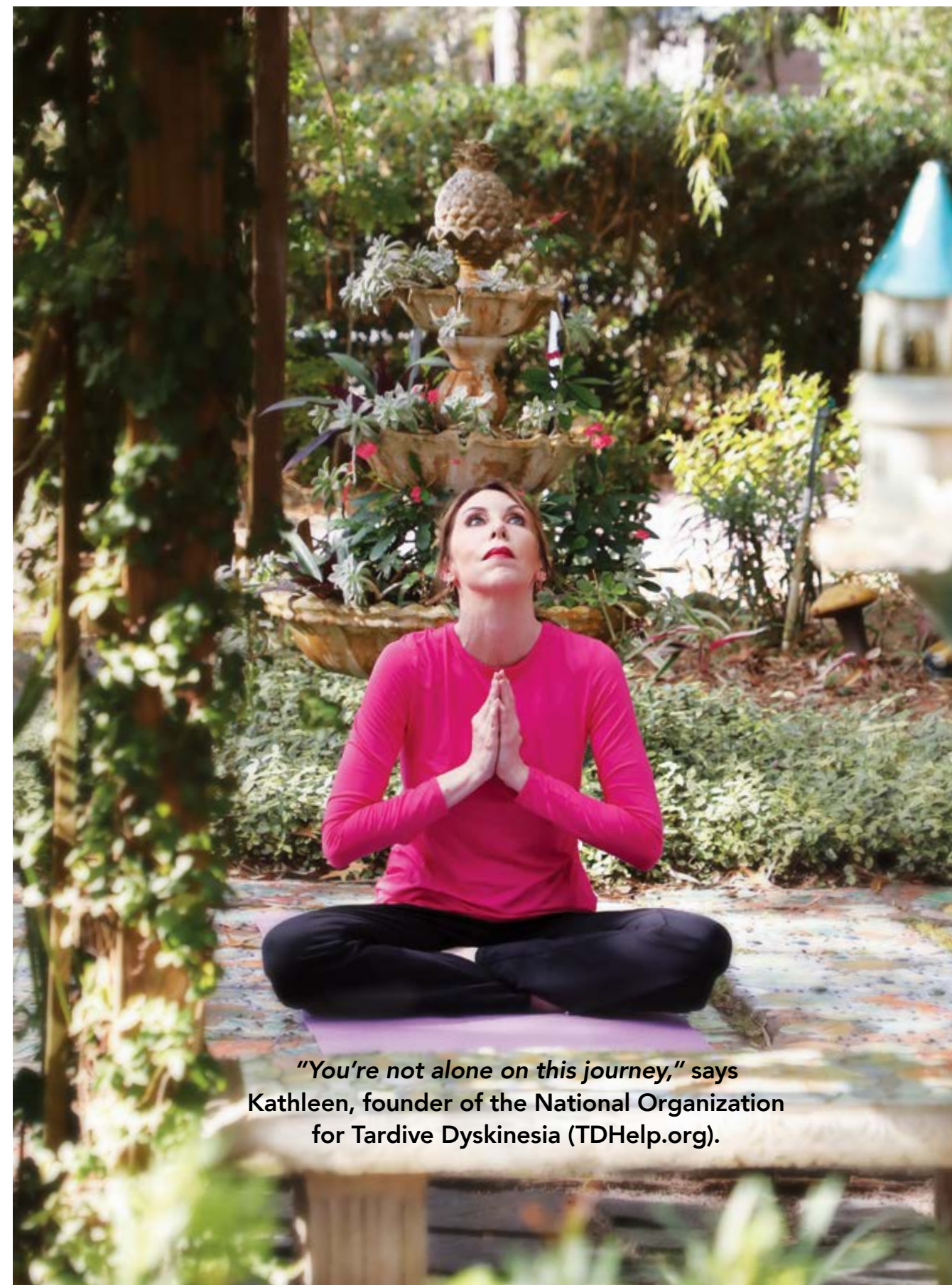
To keep the burning sensation in her mouth from flaring, she says, “I stay away from anything that has the least amount of spice in it.” Also out: acidic foods like tomato sauce and fruit juice and rough textures like pizza crust and potato chips. Instead, she focuses on mouth-soothing foods like plain yogurt, oatmeal with butter, and salmon and steak without seasoning. “For flavor, I just use a little parsley or oregano.”

Try a stress reliever

“I’ve recently started doing meditation,” she says. Even though she insists she’s “not really good at it,” that’s not quite the point—she explains the benefits are more about boosting her spirits and keeping her in a positive headspace. “It helps take my mind away,” she says.

Make a toothpaste switch

“If I use a toothpaste with a mint taste—and I’ve heard of a lot of other people with TD saying this—that either due to the sores in my mouth or the burning, I just can’t handle it,” says Kathleen. So she switched out her usual toothpaste for one that doesn’t contain any harsh ingredients that would irritate her mouth. The one she likes: Squigle Tooth Builder Toothpaste, available on amazon.com. ▶



“You’re not alone on this journey,” says Kathleen, founder of the National Organization for Tardive Dyskinesia (TDHelp.org).

“Take precautions to stay safe”

Leslie Baumgartner

Use caution at night

Like many people with TD, Leslie Baumgartner has problems with balance. So, the Southern California resident makes it a point of never walking in her home in dim lighting. “I make sure I don’t walk at night in the dark without an extra light on,” she says. As she moves around the house, Leslie flicks on all light switches to head off slips, trips and falls.

Treat your feet!

Leslie, who experiences tremors in her hands and feet, has added a regular pedicure appointment to her calendar. “I always go to a nail salon to keep my toenails trim,” she says—and that’s a must. Between the grip issues and toe spasms she experiences, Leslie finds it difficult to get the job done herself!

Rethink your footwear

“My toes stretch and relax, and sometimes stretch out in different directions in painful spasms,” says Leslie. So, she explains, “I buy quality shoes, especially ones with large toe boxes so my toes can lie flat inside.” She’s also eliminated certain footwear styles from her closet, including flip flops and heels, which she finds can worsen her balance problems.

Keep on track

“One of the most helpful things I do for my TD symptoms is to follow a schedule,” says Leslie. “I take my medications at the same time each day, and get up and go to bed at routine times.” She makes it a point



PHOTO BY JASON WARD

to stay organized in general, and keeps a journal of her symptoms and a record of her efforts to relieve her TD, whether they have a positive or negative impact. “I keep all my medically related material

together so I can speak with my healthcare professionals in a timely matter,” she says. Leslie also uses a pill box marked with days of the week so she never misses a dose.

“Work with your doctor”

Cariena Birchard

Read up

When Cariena Birchard, a legal assistant from St. Paul, NE, first started experiencing tardive dyskinesia (TD), she was scared, but learning as much as she could helped to make having the condition seem less mysterious and more manageable. Her advice is to lean on well-established organizations, such as the Depression and Bipolar Support Alliance (dbsalliance.org) and the National Alliance on Mental Illness (nami.org), to make sure you’re getting the most up-to-date information about TD. The sense of community she’s found through these organizations is also important, she says, because, “experiencing medication side effects, no matter how common they are, can be a very isolating feeling.”

Consider being upfront

As people started noticing Cariena’s symptoms, she decided to be proactive by speaking up to new acquaintances. “I tended to be open about it, sort of as a preemptive strike,” she says. By stating early on when meeting someone that she was experiencing side effects due to medication she had been on, “that made it a bit less embarrassing for me.” Despite the stigma, she insists, “I do not feel that patients should be made to feel ‘less than’ simply because mental health is a difficult subject.”

Hit the mat

Cariena says yoga has been a great addition to her life with TD. “It helps massively with the aches and pains

caused by the constant constriction of my muscles. Yoga also gave me a way to focus on something else for a little while instead of always having TD at the forefront of my brain.”

Stay open

Remaining positive and willing to try different treatments and strategies as she eliminated the ones that weren’t working for her was key for Cariena. “We went through two different medications and experimented with various stress relief exercises to find the combination that worked for me.” The lesson: Just because some strategies don’t work

for everyone doesn’t mean you won’t find one or *several* to be beneficial if you keep trying.

Communicate with your doc

“It is vital that we open up to our doctors about what symptoms and side effects—good or bad—we may be experiencing. They can’t read our minds!” says Cariena. “I have found that I am unable to progress through my mental health journey if I’m not giving my doctor a clear picture of what is going on.” Armed with knowledge, a medical professional can help determine the best course of action. 🗨️



PHOTO BY LAURA ELIZABETH PHOTOGRAPHY

5 simple ways to beat stress *(and feel your best)!*

Coping with the day-to-day symptoms of tardive dyskinesia (TD)—the uncontrollable movements that exhaust and embarrass you—can make you anxious, frustrated and undermine your confidence. Not surprisingly, all that stress can make it even harder to manage your TD, creating a vicious cycle. What you can do? Be open with your doctor about how you feel and ask for professional support. Also, consider trying these five self-help tricks that can help take the edge off.



1 Pet a furry friend. Just 10 minutes spent petting a dog or cat lowers stress, according to a study from Washington State University. Researchers say it triggers the release of oxytocin, the bonding hormone.

- **No pet?** A stuffed animal may be just as comforting, according to a British study that found a significant number of adults—women and

men—pack a “comfort doll,” such as a teddy bear, when they travel.

2 Get classical. Making dinner, doing housework or getting ready for work? Put some Bach or Vivaldi on in the background. Classical music can slow your heart rate, lower levels of stress hormones and prompt the release of feel-good

hormones. Researchers credit the tempo of classical music: At 60 to 100 beats a minute, it’s similar to a resting heart rate.

- **Have a listen!** Try Beethoven’s “Moonlight Sonata (1st Movement),” Erik Satie’s “Gymnopédie No. 1” or JS Bach’s “Prelude No. 1.” Don’t like classical? Select any music you love that helps you relax and feel good.

3 Stop multitasking. Rapidly switching from one task to another causes your body to ramp up production of cortisol and adrenaline. Overexposure to these stress hormones increases your risk for mental health disorders as well as heart disease, weight gain, digestive issues and cognitive problems.

- **A good start?** Stowing your smartphone! Studies show the average person checks their phone every 12 minutes. All that distraction not only lessens productivity, it’s also linked to depression, anxiety and aggression. Turn your phone off while you are working and schedule check-in times during the day. And turn off app notifications so you’re not interrupted by frequent pings.

4 Add some citrus to your meals. Fruits such as oranges, grapefruits and lemons are rich in vitamin C, which, studies show, helps you both cope with stress and bounce back from stressful episodes. The reason? Vitamin C prevents spikes in levels of cortisol, the stress hormone that puts your body in “fight or flight mode,” say University of Alabama researchers.

- **Not a citrus fan?** Other top vitamin C sources include red and green peppers, kiwifruit, broccoli, strawberries, Brussels sprouts, tomatoes and cantaloupe.



5 Be an early bird. People who reported greater exposure to morning light (between 8 AM and noon) not only fell asleep more easily and slept more soundly, they were less likely to report feelings of depression and stress, according to a study in the journal *Sleep Health*. Morning sunlight helps regulate your body’s natural

sleep-wake cycle and also boosts production of serotonin, the happiness hormone.

- **Maximize the benefit!** Get your morning light in a green space, whether the backyard or a nearby park. Multiple studies show a “nature hit” helps lower blood pressure, ease anxiety, lift depression and stop your mind from dwelling on negative thoughts. 🌿



Don’t let TD stop you from socializing!

Embarrassment causes some people with TD to limit their social activities. But studies show loneliness and social isolation can be just as damaging to your physical and emotional health as cigarette smoking and obesity. In addition to seeking treatment for TD, try these strategies:

Make it a teachable moment. Catch someone staring? Try saying, “I have a medical condition that brings on involuntary movements. I have no control over them.”

Keep this in mind: People who are self-conscious tend to feel others are focusing on them, according to research published in the *Journal of Experimental Psychopathology*. But it’s likely that others aren’t paying as much attention to you as you think!

Find a support person. Ask a friend, family member or loved one to help you out by joining you in everyday activities, like taking a walk in the park or grabbing a cup of coffee.



Questions to ask at today's visit

Fill out this worksheet with your doctor to make sure your treatment plan is on track.

1. Do my symptoms—my uncontrollable movements—indicate I have tardive dyskinesia (TD)?

2. What could be causing my symptoms?

3. Could my symptoms become permanent?

4. Do my symptoms indicate brain damage?

5. What treatment do you recommend to manage my symptoms? How does it work and how can it help me?

6. How will we know if I am responding to this treatment?

7. How soon can I expect to get relief from my symptoms?

8. What are the side effects I might feel? How can they be avoided?

9. What symptoms or side effects should I report to you, and when should I report them?

10. Are there any lifestyle changes I can make to ease my symptoms and feel my best?

11. Do you recommend that I see a physical therapist? If so, can you refer me to one?

12. Do you recommend that I visit any other healthcare professional?

13. Is there a clinical trial that can help me? What are the pros and cons of participating in a clinical trial?
