From Dismissal to Diagnosis: One Woman's Journey With Tardive Dyskinesia

Tardive dyskinesia (TD) can be a debilitating movement disorder and impacts hundreds of thousands of individuals in the U.S., yet remains largely underdiagnosed and undertreated.[1] Rachel Boubaker was living with unexplained, disruptive movements for six years before she advocated for herself and began her journey to a diagnosis.

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For years, Rachel Boubaker knew something was wrong — but getting someone to listen proved more challenging than she could have imagined. What began as a slight shake in her hands quickly progressed into movements in her face and body that were impossible to ignore.

Looking for answers, Rachel sought help from her healthcare provider. However, despite having highly visible symptoms, her concerns were dismissed for years before she was finally diagnosed with tardive dyskinesia (TD), a chronic movement disorder associated with long-term use of certain mental health treatments.[1]



The Reality of Living With TD

Thinking back to the years before her diagnosis, Rachel remembers how her symptoms worsened and her uncontrollable movements became more evident.

> My tongue would dart randomly, my lips would twitch and my speech would slur. A lot of people didn't know how to react to it, and some even made fun of me.

At the time, she didn't know what was causing the motions, which made it difficult for her to explain to those around her what was happening. She felt defeated and alone as everyday tasks grew more

difficult. Eventually, she could no longer walk without support, had trouble holding onto objects, found eating more difficult and was forced to give up woodworking and beading — activities that had once brought her happiness.

Beyond physical movements, TD can also impact a person's social life, daily functioning, sleep, self-esteem and mental health.[1,3,4] For Rachel, these emotional effects were just as real and disruptive as the movements themselves. What's more, the people around her started to make her feel as though she was a burden, so she began avoiding public places and social situations.

As she kept trying to figure out the reason for her uncontrollable movements, and whether there was any way to manage them, her fear of judgment continued to push her further into isolation.



Finding Answers in a Diagnosis

Rachel wanted answers. She started looking up movement disorders online, learning about her symptoms and possible causes.

The more she read about TD, the more it mirrored her own experiences. As someone taking a dopamine receptor blocking agent for her mental health condition — which carries a risk for developing TD movements — the connection felt even clearer.[4]

When she brought her findings back to the healthcare provider who previously dismissed her symptoms, they were brushed aside once again. Unfortunately, Rachel is not alone in this experience: Despite affecting over an estimated 750,000 Americans, TD is still largely underdiagnosed and undertreated.[1,2] In fact, as many as 95% of people thought to be living with TD do not receive appropriate treatment.[1]

Feeling unheard, Rachel decided to seek a second opinion. This time, thankfully, her new healthcare provider confirmed her suspicions, and she finally received her diagnosis.

> I knew it had to be TD because I had read all about it and the movements it caused. When I spoke to my new doctor and he provided me with my diagnosis, I felt incredibly validated.

After six years of uncertainty, Rachel was relieved to finally understand what was happening. And though there is no cure for TD, she felt ready to focus on ways to address her symptoms. With her healthcare team's guidance, she explored available treatment options and next steps for managing her condition.



Reclaiming Independence as a Result of Movement Improvement

Rachel was prescribed AUSTEDO XR® (deutetrabenazine) extended-release tablets, which belong to a class of medications known as vesicular monoamine transporter 2 (VMAT2) inhibitors. VMAT2 inhibitors are the only medications approved by the U.S. Food and Drug Administration to treat tardive dyskinesia.[5]

Not long after treatment with AUSTEDO XR, the once-daily formulation of AUSTEDO®, Rachel began to see noticeable improvement in her movements and as a result started regaining her independence.

After struggling with uncontrollable leg movements for a year, Rachel regained some mobility due to movement improvement.

With her TD improved, she was able to resume some daily chores, return to her hobbies and she felt more comfortable attending social gatherings with friends and family.

> For other people living with TD, I want them to understand that managing your movements does not mean you have to stop taking most mental health medications.

Whether symptoms are mild, moderate or severe, the impacts of TD can be significant, particularly when the condition remains untreated.[1] To ensure no one feels alone in their experience like she once did, Rachel is sharing her story to help others feel seen while encouraging them to advocate for their own health and inspiring them to speak with their healthcare providers about potential treatment options for TD.

"Talking to your doctor is so important, and if you feel as though you're not being heard, speak up or find another doctor who will listen," Rachel says. "More than likely, there is someone out there who can help you on your journey and find a treatment plan that works for you."

Learn more about AUSTEDO XR® (deutetrabenazine) extended-release tablets here.

Sources ⊕

IMPORTANT SAFETY INFORMATION

AUSTEDO XR and AUSTEDO can cause serious side effects in people with Huntington's disease,

including: depression, suicidal thoughts, or suicidal actions.

Do not start taking AUSTEDO XR or AUSTEDO if you are depressed (have untreated depression or depression that is not well controlled by medicine) **or** have suicidal thoughts. Pay close attention to any changes, especially sudden changes, in mood, behaviors, thoughts or feelings. This is especially important when AUSTEDO XR or AUSTEDO is started and when the dose is changed. Call your healthcare provider right away if you become depressed, have unusual changes in mood or behavior, or have thoughts of suicide.

Do not take AUSTEDO XR or AUSTEDO if you:

- have Huntington's disease and are depressed or have thoughts of suicide.
- have liver problems.
- are taking reserpine. **Do not** take medicines that contain reserpine with AUSTEDO XR or AUSTEDO. If your healthcare provider plans to switch you from taking reserpine to AUSTEDO XR or AUSTEDO, you must wait at least 20 days after your last dose of reserpine before you start taking AUSTEDO XR or AUSTEDO.
- are taking a monoamine oxidase inhibitor (MAOI) medicine. **Do not** take an MAOI within 14 days after you stop taking AUSTEDO XR or AUSTEDO. **Do not** start AUSTEDO XR or AUSTEDO if you stopped taking an MAOI in the last 14 days. Ask your healthcare provider or pharmacist if you are not sure.
- are taking tetrabenazine. If your healthcare provider plans to switch you from tetrabenazine to AUSTEDO XR or AUSTEDO, take your first dose of AUSTEDO XR or AUSTEDO on the day after your last dose of tetrabenazine.
- are taking valbenazine.

Other possible serious side effects include:

- **Irregular heartbeat (QT prolongation).** AUSTEDO XR and AUSTEDO increases your chance of having certain changes in the electrical activity in your heart. These changes can lead to a dangerous abnormal heartbeat. Taking AUSTEDO XR or AUSTEDO with certain medicines may increase this chance.
- **Neuroleptic Malignant Syndrome.** Call your healthcare provider right away and go to the nearest emergency room if you develop these signs and symptoms that do not have another obvious cause: high fever, stiff muscles, problems thinking, very fast or uneven heartbeat, or increased sweating.
- **Restlessness.** You may get a condition where you feel a strong urge to move. This is called akathisia.
- **Parkinsonism.** Symptoms include: slight shaking, body stiffness, trouble moving, trouble keeping your balance, or falls.

Sleepiness (sedation) is a common side effect of AUSTEDO XR and AUSTEDO. While taking AUSTEDO XR or AUSTEDO, do not drive a car or operate dangerous machinery until you know how AUSTEDO XR or AUSTEDO affects you. Drinking alcohol and taking other drugs that may also cause sleepiness while you are taking AUSTEDO XR or AUSTEDO may increase any sleepiness caused by AUSTEDO XR and AUSTEDO.

The most common side effects of AUSTEDO in people with Huntington's disease include sleepiness (sedation), diarrhea, tiredness, and dry mouth.

The most common side effects of AUSTEDO in people with tardive dyskinesia include inflammation of the nose and throat (nasopharyngitis) and problems sleeping (insomnia).

The most common side effects of AUSTEDO XR are expected to be similar to AUSTEDO in people with Huntington's disease or tardive dyskinesia. These are not all the possible side effects of AUSTEDO XR or AUSTEDO. Call your doctor for medical advice about side effects. You are encouraged to report side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Please read the accompanying Medication Guide.

APPROVED USES

AUSTEDO XR® (deutetrabenazine) extended-release tablets and AUSTEDO® (deutetrabenazine) tablets are prescription medicines that are used to treat:

- the involuntary movements (chorea) of Huntington's disease. AUSTEDO XR and AUSTEDO do not cure the cause of the involuntary movements, and it does not treat other symptoms of Huntington's disease, such as problems with thinking or emotions.
- movements in the face, tongue, or other body parts that cannot be controlled (tardive dyskinesia).

It is not known if AUSTEDO XR and AUSTEDO are safe and effective in children.

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