G-PACT

Gastroparesis Patient Association for Cures and Treatments, Inc.

Patient One Pager, with NOTD. Updated October 2026

TARDIVE DYSKINESIA AND GASTROPARESIS

Key takeaways from our webinar with the National Organization for Tardive Dyskinesia on managing gastroparesis medications safely

Live better by understanding more

WHAT IS TARDIVE DYSKINESIA?

TD = Tardive Dyskinesia. GP = Gastroparesis. "Tardive" means late onset and "dyskinesia" means involuntary movement. TD is a movement disorder caused by medicines that block dopamine D2 receptors in the brain. It usually appears after a medicine has been taken for a while, typically at least three months for people at average risk, and often starts in the face. TD affects an estimated 800,000 people in the U.S., and fewer than half are formally diagnosed.[1] Caught early, it can sometimes fade. In many cases it becomes permanent, which is why awareness matters.

GP MEDICATIONS AND TD RISK

Metoclopramide (Reglan) BLACK BOX WARNING

The only FDA-approved medication for GP. It speeds stomach emptying and eases nausea, but because it reaches the brain it carries a risk of TD. Risk grows with total dose and time on the drug.[2]

Domperidone LOW BRAIN EXPOSURE

Not FDA approved in the U.S. but available through an FDA expanded access program. It mostly stays outside the brain, so TD risk is generally low. Ask your gastroenterologist about current access.

THE 12-WEEK RULE AND DRUG HOLIDAYS

The FDA advises against taking metoclopramide for more than 12 weeks except in rare cases where benefit outweighs risk. It should be stopped right away if signs of TD appear, and not used by anyone with a past history of TD. For people at average risk who stay within 12 weeks, recent research suggests the risk is likely under 1 percent, much lower than the 1 to 10 percent once estimated.[3]

Many patients take planned "drug holidays" of 2 to 4 weeks between 12-week courses to lower their total exposure, an approach supported by new research released after the webinar.[4] During breaks, your gastroenterologist may suggest another prokinetic such as erythromycin, a non-dopamine anti-nausea medicine, or smaller, low-fat, low-fiber meals.

WHO IS AT HIGHER RISK?

- Adults over 50, rising further after 65, and women more than men[5]
- Diabetes or reduced kidney function
- Also taking antipsychotics or other dopamine-blocking anti-nausea drugs
- Higher doses or longer treatment
- Past lithium use, or unusually slow or fast CYP2D6 drug metabolism
- Smoking, or a history of alcohol or substance use

For people at high risk, TD can appear within a month.

EARLY SIGNS TO WATCH FOR

- **Face first:** tongue moving or darting out, lips rubbing together, grimacing, facial twitching, rapid blinking
- **Anywhere in the body:** flowing "piano fingers," gripping or "dancing" toes, jerking of the hands, feet, or torso, trouble chewing, swallowing, speaking, or breathing, balance problems, brain fog

Many people do not notice their own movements, so ask a loved one to speak up if they see something. FDA-approved treatments exist: valbenazine (Ingrezza) and deutetrabenazine (Austedo).

THE ER QUESTION: TD OR AKATHISIA?

Tardive dyskinesia

Develops slowly, usually after months on a medicine. Repetitive involuntary movements, often in the face.

Akathisia

Can start soon after a medicine is started, changed, or stopped, including during an ER IV "cocktail." Pacing, panic, a feeling of needing to crawl out of your skin.

Both deserve to be taken seriously. In the ER, ask what each medicine is for, whether it blocks dopamine, and whether there is an alternative if you have reacted badly before. **Never stop or change a medication on your own.** Talk with your doctor first.

> *"Let facts, not fear, drive your decisions."*
>
> **Bill Cote, Executive Director, National Organization for Tardive Dyskinesia**

LEARN MORE AND GET SUPPORT

This one pager covers the essentials. The full article and webinar go deeper, including April Kraft's firsthand account of living with TD and the human impact of the condition.

Read the full article and watch the webinar
Article: g-pact.org/blog
Webinar: youtube.com/@GPACT_nonprofit
717-356-0052

National Organization for Tardive Dyskinesia
tdhelp.org
866-TDHELP1 (866-834-3571), virtual support groups

You are the expert on your own body. Ask questions, and keep asking.

NOTES

1. Estimates range from 500,000 to 800,000 Americans, and all sources agree most are undiagnosed (Neurocrine Biosciences, NAMI, Mental Health America, Psychiatric Times).
2. FDA labeling directs prescribers to stop metoclopramide if TD signs appear, avoid use beyond 12 weeks, and not use it with a history of TD.
3. Estimates vary by method and population: below 1% (Rao and Camilleri, 2009); about 0.1% (DDW 2022); no independent link after adjustment (McCallum et al., 2026). Several studies received industry support.
4. Since the webinar: a September 2026 study of about 125,000 people with GP on oral metoclopramide found lower TD rates and later onset with planned breaks than with continuous use, with rates of 0.25% to 0.77%. The 2025 AGA guideline suggests holidays of 1 to 4 weeks every 8 to 12 weeks. Russo, Nathan, Camilleri, Neurogastroenterology & Motility, 2026; supported by Evoke Pharma; based on claims data. Free full text: pmc.ncbi.nlm.nih.gov/articles/PMC13547634
5. Age thresholds differ by source, from 40 to 55. Higher risk in older adults and women is consistent across the literature.

This one pager is for educational purposes only and summarizes a G-PACT webinar presented with the National Organization for Tardive Dyskinesia, with research updates added after the webinar. It does not replace medical advice. Treatment decisions should always be made with a qualified healthcare provider based on your individual circumstances.

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