MALISSA PISTILLO

Dear Doctor

BENZODIAZEPINE

Dear Doctor,

My name is Malissa Pistillo, and I am writing to you as a psychotropic drug harm awareness advocate and survivor. I want to begin by outlining what patients like myself are asking of prescribers when it comes to ongoing benzodiazepine prescriptions — and especially when considering whether and how to safely come off these medications.

What We Are *Asking*

Shared decision-making — Patients and caregivers should be fully informed and included in the choice of whether to continue or taper benzodiazepines, as emphasized in the ASAM Benzodiazepine Tapering Guideline (2025).[2]

Gradual, hyperbolic tapering — Please individualize reductions and slow further at lower doses (a hyperbolic pattern). Experts generally suggest starting with 5–10% reductions, but some patients will require going as low as 2% every few weeks or longer, particularly at the lowest doses. Expert guidance also recommends tapering to well below minimum therapeutic doses to mitigate withdrawal.[8] (See also Horowitz & Taylor, Maudsley Deprescribing Guidelines, 2024.)[4]

Accurate recognition of withdrawal vs. relapse — Many withdrawal syndromes, including protracted ones, are misdiagnosed as relapse or pre-existing psychiatric illness. This mistake leads to inappropriate treatment and unnecessary suffering.

Access to safe formulations — Compounded or liquid preparations should be available to allow very small, precise dose reductions.

Recognition of akathisia — a high-risk withdrawal phenomenon that is frequently misdiagnosed. It is not merely a movement disorder but an intense inner agitation and distress strongly associated with suicidality; it warrants prompt recognition and an urgent, appropriate clinical response, with alignment to the patient's experience and supportive measures.[9] In some cases, the safest course is to provide reassurance, careful monitoring, and space for the nervous system to heal.

FDA Guidance

In September 2020, the U.S. Food and Drug Administration (FDA) issued a Drug Safety Communication warning of serious risks associated with abrupt or overly rapid discontinuation of benzodiazepines. The FDA stated:

> "*Use a gradual taper to reduce the dosage or to discontinue benzodiazepines to reduce the risk of acute withdrawal reactions.*"
> (U.S. Food and Drug Administration, 2020, Drug Safety Communication, September 23).[1]

The FDA also emphasized that there is no standard tapering schedule suitable for all patients and that tapering must be individualized.

Dependence vs. Addiction (and Patient Choice)

The **American Society of Addiction Medicine (ASAM) 2025 Benzodiazepine Tapering Guideline** provides critical clarification that is often misunderstood in medical practice[2]:

> *"Physical dependence is a biological phenomenon that develops in response to repeated use of a medication... Conversely, substance use disorder is a chronic disease associated with functional changes to the brain circuits that mediate stress, decision-making, and behavior reinforcement."*
>
> *"Physical dependence is an expected outcome associated with BZD use and is distinct from BZD use disorder."*
>
> *"Clinicians should...utilize shared decision-making strategies."*

> ASAM further cautions: *"Clinicians should not presume that patients with physical dependence have an SUD."*

This distinction is reinforced in the FDA-approved DailyMed prescribing information for Benzodiazepines, which states:

> *"Physical dependence is not the same as drug addiction. Your healthcare provider can tell you more about the differences between physical dependence and drug addiction."*
> *(DailyMed)*[3]

Unfortunately, this distinction remains highly misunderstood in the medical system, where patients in withdrawal are frequently mislabeled as "addicted" or diagnosed as relapsing into their underlying condition. In reality, most such cases represent **iatrogenic withdrawal**, not addiction or relapse.

Protracted Withdrawal Syndrome

Protracted Withdrawal Syndrome (PWS)

is when withdrawal symptoms last for months or years after stopping a psychiatric drug. It often happens when benzodiazepines or other meds are reduced too quickly, leaving the brain—after adapting to the drug—overstimulated and struggling to rebalance. Symptoms can include anxiety, insomnia, sensory problems, cognitive issues, akathisia, and much more.

Some clinicians, researchers, and advocacy groups now also use the term BIND (Benzodiazepine-Induced Neurological Dysfunction) to refer to the same phenomenon. BIND has been proposed in scientific literature (e.g. the 2023 survey by Ritvo et al.)[10] to describe persistent neurological and functional impairment that may begin during use or tapering and continue long after drug discontinuation.[10]

It is used by nonprofit advocacy groups such as BenzoReform, Benzodiazepine Information Coalition and others to help communicate more clearly the brain-related injury aspect of these symptoms, which many patients find more validating.[11] [12]

A patient may feel more comfortable or better understood using the term “BIND,” since it emphasizes that the symptoms are not just lingering withdrawal but represent a kind of neurological dysfunction or injury that requires support, validation, and careful management.

Both FDA labeling and the ASAM 2025 Benzodiazepine Tapering Guideline explicitly recognize Protracted Withdrawal Syndrome (PWS) as a serious clinical entity:

FDA, Diazepam Label (DailyMed):[3]

“Prolonged use of benzodiazepines may result in dependence, which may include protracted withdrawal syndrome lasting weeks to more than 12 months.”

ASAM 2025 Guideline:[2]

ASAM dedicates an entire section to Management of Protracted Withdrawal. It emphasizes that symptoms may persist long after drug discontinuation and require sustained medical support. The guideline advises clinicians to:

- Recognize PWS as distinct from relapse.
- Validate patient reports of long-lasting symptoms.
- Provide non-pharmacological supports such as psychoeducation, coping strategies, and reassurance.
- Avoid rapid re-exposure to benzodiazepines unless absolutely necessary.

ASAM’s inclusion of PWS in its national guideline is a significant shift — formally acknowledging what patients have long reported: withdrawal may not resolve within days or weeks, but may persist for many months or even years.
tient-centered, flexible tapering.[2] [3] [4]

PWS as a Form of Brain Injury

Emerging evidence suggests that protracted withdrawal reflects a neurobiological injury caused by chronic benzodiazepine exposure and the brain's compensatory adaptations:

Neuroadaptation Mechanisms:

Long-term benzodiazepine use downregulates and uncouples GABA_A receptors while upregulating glutamatergic excitatory pathways. This leaves the nervous system in a state of hyperexcitability once the drug is withdrawn Vinkers & Olivier, European Journal of Pharmacology, 2012, [7] Griffin et al., Neuropharmacology, 2013).[8]

Brain Injury Analogy:

Professor Heather Ashton, in The Ashton Manual (2002),[5] described protracted withdrawal as a type of drug-induced brain injury, noting that recovery involves "slow healing and re-adaptation of the central nervous system."

Clinical Literature:

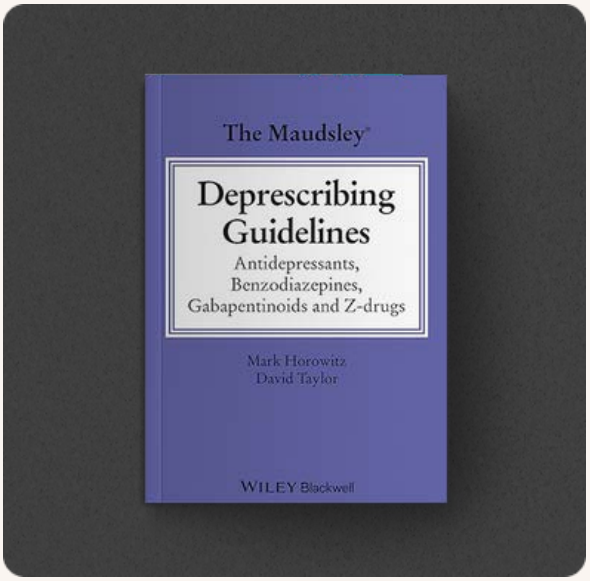
A review by Lader (2011, Addiction) stated: "Protracted withdrawal syndromes… may be conceptualized as persisting neurochemical imbalances or damage caused by long-term benzodiazepine use."[6]

Patient-Reported Outcomes:

Large surveys document persistent neurological, cognitive, and autonomic symptoms lasting months to years, often mistaken for psychiatric relapse but more consistent with iatrogenic injury to neural systems.

Gold-Standard Tapering Guidance

Two highly regarded resources form the foundation of safe deprescribing:



The Maudsley Deprescribing Guidelines (Horowitz & Taylor, 2024)[4]

which emphasize hyperbolic tapering, patient-led pacing, and the risk of misdiagnosing withdrawal as relapse. The authors state: *"Go slowly… and proceed even more cautiously for the last few milligrams."*

The Ashton Manual (Ashton, 2002, University of Newcastle)[5]

a classic manual on benzodiazepine withdrawal that provides practical methods, including diazepam substitution and gradual reduction. *(Note: Transitioning to a longer half-life benzodiazepine is not always seamless for every patient, and clinicians should work closely with each individual to determine what is most tolerable and effective for them)*

Both stress the importance of hyperbolic, individualized tapers. For some patients, this may mean reductions as small as 2% every few weeks or longer, particularly at the lowest doses.

Neurobiology: Why Slow Tapering Matters

Physical dependence on benzodiazepines can develop in as little as two weeks of regular use, and longer-term use leads to well-documented neuroadaptations:

> *"A person who takes a potent benzo once a day for as little as two weeks can experience a mild withdrawal upon stopping. The higher the dose … the more severe dependence can become."*
> (Krieger et al., 2025, Frontiers in Psychiatry)[13]

Downregulation and uncoupling of GABA_A receptors

⟶ reduced inhibitory function.[7]

Upregulation of glutamatergic systems, including NMDA receptors

⟶ excess excitatory signaling.[8]

These changes explain the hyperexcitability of withdrawal (e.g., anxiety, insomnia, seizures) and underscore the need for very gradual, hyperbolic tapers (Vinkers & Olivier, 2012; Griffin et al., 2013).[7]

Withdrawal Symptoms (and Misdiagnosis Risks)

Withdrawal can produce **over 200 distinct symptoms** documented in the medical literature and patient reports. Common categories include:

- **Neurological**: tremor, paresthesias, tinnitus, muscle twitching, seizures.
- **Psychiatric**: severe anxiety, panic, depression, depersonalization/derealization, intrusive thoughts.
- **Autonomic/physical**: palpitations, sweating, GI upset, temperature dysregulation.
- **Cognitive**: impaired concentration, memory problems, confusion.
- **Akathisia**: one of the most dangerous and misunderstood symptoms. Akathisia is not simply a movement disorder but a syndrome of extreme inner restlessness, agitation, and “inner torment,” often accompanied by suicidal ideation or impulses (Akagi & Kumar, BMJ, 2002).[9]

Too often, physicians mistake these withdrawal symptoms for relapse of the underlying condition. This misunderstanding can lead to misdiagnosis, stigmatization, and inappropriate continuation of medications.

Closing

Too often, physicians mistake these withdrawal symptoms for relapse of the underlying condition. This misunderstanding can lead to misdiagnosis, stigmatization, and the inappropriate continuation of medications. Thank you for considering this patient-safety perspective grounded in current evidence. I respectfully ask that you work in partnership with your patient to develop an individualized, symptom-paced taper plan that prioritizes function, informed consent, and minimizes iatrogenic harm.

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ACCESS LIVE TEXT OF LETTER

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