

MALISSA PISTILLO

Dear Doctor

BENZODIAZEPINE REQUEST
FOR SHARED DECISION-MAKING
ON BENZODIAZEPINE THERAPY



Dear Doctor,

I am writing to you as a patient who has been prescribed a benzodiazepine by your care or within the medical system. I deeply value your expertise and the therapeutic relationship we share. However, I am requesting that any decision to discontinue or reduce my benzodiazepine prescription be made collaboratively — based on shared decision-making, informed consent, and the current scientific and regulatory guidance from the U.S. Food and Drug Administration (FDA) and the American Society of Addiction Medicine (ASAM)¹².

1. Patient Autonomy and Shared Decision-Making

The ASAM Benzodiazepine Tapering Guideline (2025) states that:

“Clinicians should utilize shared decision-making strategies when determining whether to continue or taper benzodiazepines. Physical dependence alone does not constitute a substance use disorder.”²

Informed consent includes the right to accept or decline treatment changes, particularly when those changes may cause harm. The ASAM guideline makes clear that continued maintenance therapy can be appropriate when discontinuation risks outweigh benefits, or when prior attempts at tapering have resulted in significant withdrawal or functional decline².

2. FDA Position: Individualized and Patient-Centered Care

In its 2020 Drug Safety Communication, the FDA warned:

“Use a gradual taper to reduce the dosage or to discontinue benzodiazepines to reduce the risk of acute withdrawal reactions.”¹

“There is no standard tapering schedule suitable for all patients; tapering must be individualized.”¹

The FDA also emphasizes that **physical dependence is an expected biological response**, not evidence of misuse or addiction. The official labeling on DailyMed for diazepam and other benzodiazepines states:

“Physical dependence is not the same as drug addiction.”³

For many patients, remaining on a stable, low dose is the most appropriate and safest clinical course. Forcing rapid or involuntary discontinuation can constitute a deviation from FDA safety guidance and may expose patients to significant medical risk¹³.

3. Medical Evidence of Harm from Forced or Rapid Discontinuation

Research demonstrates that abrupt or coerced tapering can result in severe and prolonged withdrawal syndromes, sometimes lasting months or years, known as Protracted Withdrawal Syndrome (PWS) or *Benzodiazepine-Induced Neurological Dysfunction (BIND)*⁷. Symptoms may include anxiety, akathisia, derealization, autonomic instability, and suicidal ideation.

ASAM explicitly recognizes PWS as a legitimate clinical condition requiring ongoing medical support and validation:

“Symptoms may persist long after discontinuation and should not be misinterpreted as relapse.”²

The FDA’s DailyMed label for diazepam further warns:

“Prolonged use of benzodiazepines may result in dependence, which may include protracted withdrawal syndrome lasting weeks to more than 12 months.”³

4. Dependence Is an Iatrogenic Condition, Not a Moral Failing

Long-term benzodiazepine use produces measurable neuroadaptations: downregulation of GABA_A receptors and upregulation of excitatory pathways⁵⁶. These changes make withdrawal physiologically difficult and sometimes dangerous. When dependence arises from medically prescribed use, it should be recognized as iatrogenic dependence — a predictable pharmacological outcome of long-term therapy, not a disorder of behavior or choice.

5. Potential Risks of Continued Benzodiazepine Use

While I recognize the potential benefits of ongoing therapy, I also want to make a fully informed decision about my treatment. Therefore, I respectfully ask that you share up-to-date medical information about the potential long-term risks associated with benzodiazepine use, including but not limited to:

- Cognitive decline and dementia risk: Several large cohort studies (e.g., Billioti de Gage et al., BMJ, 2014) have shown a possible association between chronic benzodiazepine use and increased risk of dementia⁸.
- Falls and fractures: Meta-analyses (e.g., Woolcott et al., J Am Geriatr Soc, 2009) report that benzodiazepine use approximately doubles fall risk, particularly in older adults⁹.
- Sedation and psychomotor impairment: FDA labeling warns of residual sedation, slowed reaction time, and impaired coordination that may affect driving and daily function³.
- Organ system considerations: Long-term use has been linked in some studies to hepatic metabolism strain and potential respiratory depression when combined with CNS depressants¹⁰.
- Tolerance and reduced efficacy: Prolonged use may result in receptor desensitization, reducing therapeutic benefit over time⁵⁶.

Understanding both the potential benefits and risks is essential for true informed consent and will help guide my personal decision about whether to continue or consider a gradual, patient-led taper.

6. Clinical and Ethical Rationale for Allowing Ongoing Maintenance

For some patients, especially those with stable functioning, forced discontinuation violates key medical ethics principles — nonmaleficence (do no harm) and autonomy. The ASAM guideline and FDA communications both stress that continuation may be appropriate when the risks of withdrawal exceed potential benefits¹². Many patients experience improved quality of life, stability, and functionality with carefully monitored long-term therapy.

7. A Respectful Request

I respectfully ask that:

- You recognize my right to participate fully in this decision.
- No reduction or discontinuation be initiated without my informed and voluntary consent.
- If any taper is ever considered, it follows evidence-based guidance: hyperbolic, individualized, and symptom-paced⁴.
- You provide full disclosure of both benefits and risks associated with ongoing benzodiazepine therapy, including cognitive and physical health considerations⁸⁹¹⁰.
- The goal of care remains function and stability, not drug elimination at all costs.

I am committed to working collaboratively with you — but I ask that my physiological reality, lived experience, and the clear guidance of national authorities (FDA, ASAM) be honored. This is my body, my mind, and my right to safe, informed medical care. Thank you for understanding and for practicing medicine that respects both science and patient autonomy.

Respectfully,

Your Patient

Key References

- 1 U.S. Food and Drug Administration. Drug Safety Communication: Boxed Warning Updated for Benzodiazepines. September 23, 2020.
- 2 American Society of Addiction Medicine (ASAM). Joint Clinical Practice Guideline on Benzodiazepine Tapering. February 2025.
- 3 DailyMed. Diazepam Label. U.S. National Library of Medicine.
- 4 Horowitz, M., & Taylor, D. *The Maudsley Deprescribing Guidelines*. Wiley-Blackwell, 2024.
- 5 Vinkers, C.H., & Olivier, B. "Mechanisms underlying tolerance after long-term benzodiazepine use." *European Journal of Pharmacology*. 2012;682(1-3):27-37.
- 6 Griffin, C.E., et al. "Benzodiazepine pharmacology and CNS-mediated effects." *Neuropharmacology*. 2013;63(4):243-256.
- 7 Ritvo, E.C., et al. "Benzodiazepine-Induced Neurological Dysfunction (BIND): Patient Experiences from an International Survey." *Frontiers in Psychiatry*. 2023;14:1166865.
- 8 Billioti de Gage, S., et al. "Benzodiazepine use and risk of dementia: prospective population-based study." *BMJ*. 2014;349:g5205.
- 9 Woolcott, J.C., et al. "Meta-analysis of the impact of medications on fall risk in the elderly." *J Am Geriatr Soc*. 2009;57(3):513-520.
- 10 Votaw, V.R., et al. "The epidemiology of benzodiazepine misuse: a systematic review." *Drug Alcohol Depend*. 2019;200:95-114.

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