### MALISSA PISTILLO

# Dear Mom



## Dear Mom,

I need to share something very important with you, and I want to do it with honesty and love. I was prescribed psychiatric medication that I was told was safe to take daily, even long-term. What I didn't know—and what my doctor never explained—is that these drugs can cause something called *neuroadaptation*. That means the brain and nervous system adapt to the drug, and when that happens, the body can become **dependent**. For some people, harm can come quickly, and too often it's misdiagnosed as a new mental illness, leading to more labels and more prescriptions.

What I also wasn't told is that these drugs can cause **neurological injury**—changing mind, body, and spirit in ways no one ever warned me about. This is not something I ever expected, or would wish on anyone, but now it's the journey I have to walk.

One of the hardest effects is something called **Akathisia**. It's well-documented across all psychiatric drugs, but most doctors are not educated about it. It's not just a movement disorder that makes me restless—it's an inner torment, a state that alters consciousness itself, flooding me with dark, racing thoughts. It is closely linked to suicidality, yet often misunderstood. Please know: those thoughts are not really me. They are the byproduct of drug-induced injury to my nervous system.

I may also be living with **Protracted Withdrawal Syndrome (PWS)**. Both the FDA and the American Society of Addiction Medicine (ASAM, 2025) now formally recognize PWS as a serious condition. Symptoms can last months or even years after a drug is out of my system because the nervous system is struggling to heal. This can include anxiety, insomnia, cognitive problems, sensory disturbances, akathisia, and more. **In the case of benzodiazepines, this injury is often referred to as Benzodiazepine-Induced Neurological Dysfunction (BIND).** Professor Heather Ashton described it as a form of drug-induced brain injury, and newer research suggests brain receptors are disrupted and need time—sometimes a long time—to re-balance.

It's important to understand that *dependence is not the same thing as addiction*.

Dependence is a physical, biological process that happens when the brain adapts to repeated exposure to a drug. Addiction, on the other hand, involves craving, compulsion, and destructive behavior to seek out a substance. I didn't choose this, I didn't abuse my medication, and I'm not addicted—I am dependent. In fact, many people say dependence can feel even worse than addiction, because the withdrawal itself causes lasting neurological injury and unbearable suffering. Unfortunately, doctors often confuse the two, which leads to stigma and mistreatment instead of compassion.

That's why experts now recommend *hyperbolic tapering*—reductions of 5–10% (or even as little as 2%) every few weeks or longer, going slower at the lowest doses, to reduce injury risk (Horowitz & Taylor, *Maudsley Deprescribing Guidelines*, 2024). Despite this, harm still happens: about **1 in 6** people on benzodiazepines and **1 in 10** on antidepressants may be injured in this way.

Mom, I am writing this because I need you to understand that this is not who I truly am. The pain, the agitation, the dark thoughts—they are all side effects of psychiatric drug injury. I will heal, but it will take time. And while I fight through withdrawal and protracted symptoms, I need your support more than ever.

Please don't give up on me. Even if I say horrible things in despair, even if I cry or beg for relief, please stay by my side. Those words are not me, but a byproduct of the harm. Help me when and how you can—maybe with groceries, rides, or a meal when I'm too tired to cook. Maybe just by sitting beside me while I cry. If you're in a position to help financially, even in small ways, it would mean more than I can say. And if not, your presence is already a gift. I don't need you to fix this—because you can't. I simply need your love, your presence, and your support when and where you are able. That alone will mean everything to me.

### And Mom, please remind me often of these things, because they will keep me grounded as best as possible and alive when I forget:

- Tell me I will heal, with conviction.
- Tell me it's not okay what I'm going through, and it's okay to feel angry, to yell, and to cry. Please never tell me to stop crying—just hold me or hold space through it.
- Tell me I am the strongest person you have ever met.
- Tell me that there is meaning and purpose in this experience, even if I don't see it now—that I will understand when I make it through to the other side.
- Remind me that some people heal rapidly or even have miraculous turnarounds, and that this could be possible for me too.
- Tell me my only job is to keep a pulse and make it to the next day.
- Remind me again and again: this isn't truly me—it's the injury, not my essence.
- Tell me that my spirit, my soul, my true self is still here, waiting for me to heal into it again.
- Tell me that healing happens slowly, but it does happen, and every day my nervous system is working to repair itself.
- Tell me you believe in me and that I will get my life back.

And Mom, just as important—please avoid saying the things below; in the middle of injury and withdrawal they can feel invalidating and make symptoms worse:

- "You're lazy." / "Suck it up." / "Pull yourself together."
- "It's all in your head." / "You're being dramatic."
- "Push harder." / "Power through." / "Just go to the gym."
- "There's no such thing as antidepressant or benzo withdrawal or injury."
- "I need you to do more" when I'm symptomatic.
- "Stop crying." / "Calm down."
- "You should be over this by now" or comparisons to others.
- "If you really wanted to get better, you would."
- "Just take whatever the doctor gives you" or "this is your fault."
- "You look fine." / "Everyone feels like this." / "Others have it worse."
- "We don't need to tell anyone about this." / "You're ruining things for the family."
- "This is who you are now."

I know this may be hard to understand, but I ask you to try. Please read the materials I share with you, so you can see the science behind what I'm going through. Millions of people worldwide have suffered this same injury, many not even knowing it, and many are walking the same path now. I never expected to be one of them—but I need your love, patience, and strength as I walk this path toward healing.

With all my love,

your child

#### References & Resources

- Benzodiazepine Information Coalition <u>www.benzoinfo.com</u>
- 2 Antidepressant Coalition <u>www.antidepressantcoalition.org</u>
- Horowitz, M., & Taylor, D. (2024). *The Maudsley Deprescribing Guidelines*: Antidepressants, Benzodiazepines, Gabapentinoids and Z-drugs. Amazon (print): <a href="https://www.amazon.com/Maudsley-Guidelines-prescribing-Prescribing/dp/111982298X">https://www.amazon.com/Maudsley-Guidelines-prescribing-Prescribing/dp/111982298X</a>
- Heather Ashton (2002). *The Ashton Manual* Classic resource on benzodiazepine withdrawal. <a href="https://www.benzo.org.uk/manual/">https://www.benzoinfo.com/ashtonmanual/</a>).
- BIND Study (2022–2023) Research on Benzodiazepine-Induced Neurological Dysfunction (BIND), highlighting lasting withdrawal injury. https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0285584
- Hengartner, M. P., Schulthess, L., Sørensen, A., & Framer, A. (2020). Protracted withdrawal syndrome after stopping antidepressants: A descriptive quantitative analysis of consumer narratives from a large internet forum. *Therapeutic Advances in Psychopharmacology*, 10, 2045125320980573. <a href="https://doi.org/10.1177/2045125320980573">https://doi.org/10.1177/2045125320980573</a>
- Advocate sharing lived experience, education, and resources: The Face of Malpractice (TikTok: https://www.tiktok.com/@thefaceofmalpractice) and Malissa Pistillo (malissapistillo.com).

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