



ON THE LEVEL
MAGAZINE

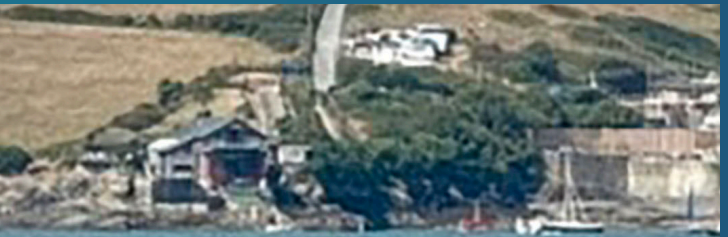
SPRING 2026

STRENGTH IN THE UNSTEADY

Sam's struggle with unexplained vertigo, and the ups and downs she faced on her journey to managing her condition and reclaiming her life.

PAGES 3-6

SHE CAN EVEN WALK ON THE BEACH AGAIN!



VEDA

A QUARTERLY MAGAZINE
OF THE VESTIBULAR
DISORDERS ASSOCIATION

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STRENGTH IN THE UNSTEADY

By Samantha Jarvis

My name is Sam, though many people know me as Diary of a Dizzy Mummy, a name that grew out of sharing my lived experience through my social media videos, the hard days, the hopeful ones, and everything in between.

BEFORE THE VERTIGO

Before my vestibular disorder, I was a chef and baker, working in busy kitchens and bakeries. The days were demanding—high pressure, long hours, constant movement—but I loved it. I thrived in the intensity of service and the creativity my role allowed me to bring to life.

Shortly before my symptoms began, I had my first child. I was on maternity leave, soaking up every moment of motherhood. It was a completely different pace of life, slower and softer, but I adored those months: a season of joy and connection.

SUDDENLY, EVERYTHING CHANGED

In my mid-twenties, my symptoms began completely out of nowhere.

I'd had a lovely day with my daughter. We'd just come home from the park and



FOLLOW SAM ON INSTAGRAM @DIARYOFADIZZYMUMMY

sat down to have some lunch. Suddenly, as I was sitting on the sofa, I felt the room start to move. It was the strangest sensation, and it kept growing and growing. Alongside the vertigo came confusion. I couldn't remember my name or where I was.

I reacted as most people would. I panicked. I ended up in an ambulance on the way to the A&E ("Accident and Emergency" in the UK).

That day, I was told "All your tests are fine." A sentence that should have been reassuring, but wasn't because I was definitely not fine.

From that day on, I deteriorated over the



course of months. I reached a point where I couldn't do anything. I couldn't stand, I couldn't lie down, I couldn't do anything without experiencing severe vertigo. I couldn't care for my daughter. I needed my husband or a family member with me constantly, just to get through the day.

THE MYSTERY ILLNESS

I spent months seeing my general practitioner, visiting the A&E, and consulting multiple specialists, only to hear the same line over and over: "All your tests are fine."

It was frustrating and isolating. I knew something was wrong, but no one could tell me what.

Everything changed the day I found a neuro-otologist who specialized in balance disorders. Finally, someone understood the complexity of my symptoms.

That visit gave me a diagnosis: vestibular migraine and PPPD.

It was a relief to have an explanation, a name for what I was experiencing, and a path forward. It gave me closure for all those unanswered questions and I finally felt seen.

MANAGING HER CONDITION

Over the years that followed, I tried countless medications. Some worked remarkably well and allowed me long stretches where my symptoms felt manageable, but the dizziness has never fully disappeared.

Today my treatments include migraine Botox and Vyepti infusions. They have helped me reclaim a quality of life I once feared I had lost.

Lifestyle changes have also become a cornerstone of my treatment. Diet, in particular, plays a crucial role. Staying well hydrated, prioritising sleep, and reducing stress (as much as you can with three young children that is) have

made a real difference. Perhaps the most important shift has been learning to truly listen to my body: recognising when I need to rest and when gentle movement will help me heal.

UNDERSTANDING HER LIMITS

I've learned to accept that I may never be completely symptom-free, and I've made peace with that reality.

I've had to let go of the belief that I should be able to do everything, all

FOR ME, SUCCESS IS NO LONGER ABOUT PERFECTION. IT'S ABOUT REACHING THE HIGHEST LEVEL OF WELLNESS POSSIBLE AND BUILDING A LIFE WITHIN THOSE LIMITS.



the time. Accepting my limits hasn't meant giving up; it's been an act of self compassion, and one that has allowed me to live more fully within the life I have.

For me, success is no longer about perfection. It's about reaching the highest level of wellness possible and building a life within those limits.

A NEW LIFE WITH NEW JOYS

My life has changed in ways I never imagined or planned for.

While it doesn't look like the future I once envisioned, I am deeply grateful for what it holds today. I'm especially grateful for my three wonderful children, whom I am now able to care for independently, something that felt

impossible in the early days.

I am very lucky to have a supportive husband and family whose patience and encouragement have kept me steady when life (and my balance) felt anything but!

I'm not able to work at the moment, and I don't yet know if returning to a kitchen environment will ever be possible, as it remains a significant trigger for my symptoms. That uncertainty is difficult to sit with.

However, in a way I never expected, I've found my way back to baking. Being able to make cakes at home again for family and friends—something I hadn't managed for several years—has brought me a quiet joy and a sense of connection to a part of myself I thought I'd lost. >

A LIFELINE WHEN SHE TRULY NEEDED IT

A couple of years ago I suffered a major relapse. As my physical symptoms intensified, my mental health deteriorated alongside them.

Without VeDA and the wider vestibular community, I honestly don't know where I would be today... or if I would still be here at all.

In VeDA, I found understanding, validation, and a sense of belonging when I felt most alone. Knowing that others truly understood what I was living through made all the difference.

For many years, I carried so much sadness, anger, and a deep sense of unfairness about the hand I was dealt. But over time, my perspective has shifted. What once felt like only loss has given me a kind of superpower: the ability to truly understand, support, and walk alongside others who are just beginning to find their feet.

It was the support I received through VeDA that helped me find my purpose, raising awareness and helping others who are walking this same path.

I felt incredibly alone for a long time, until I found VeDA and the community that reminded me I wasn't. After everything I've been through, I want to be the person I needed at the very start of my vestibular disorder. Someone who listens,

understands, and believes.

While the journey is ongoing, I move forward with resilience, gratitude, and a deep commitment to ensuring no one else feels as isolated as I once did.

SAM'S MESSAGE TO THOSE WHO ARE STRUGGLING

If you're at the beginning of your vestibular journey, please know this: you're not weak, you're not imagining it, and you're not alone. What you're feeling is real, and it's okay to grieve the life you had while you learn how to live this new one. Please reach out, ask questions, and lean on the vestibular community, we are here for you.

YOU ARE THE LIFELINE FOR PEOPLE LIKE SAM

Sam's message to anyone who is able to give, whether it's \$5 or \$500:

"A gift to VeDA is more than a donation, it's a lifeline. It provides education, connection, and hope to people navigating vestibular disorders, often at their lowest point. For some, that support can truly make the difference between coping and feeling completely lost... and it may even save a life."

You can change a life when you give today at [VESTIBULAR.ORG/DONATE](https://www.ve.org/donate)

HONORING THE IMPACT OF DANIA MOSS

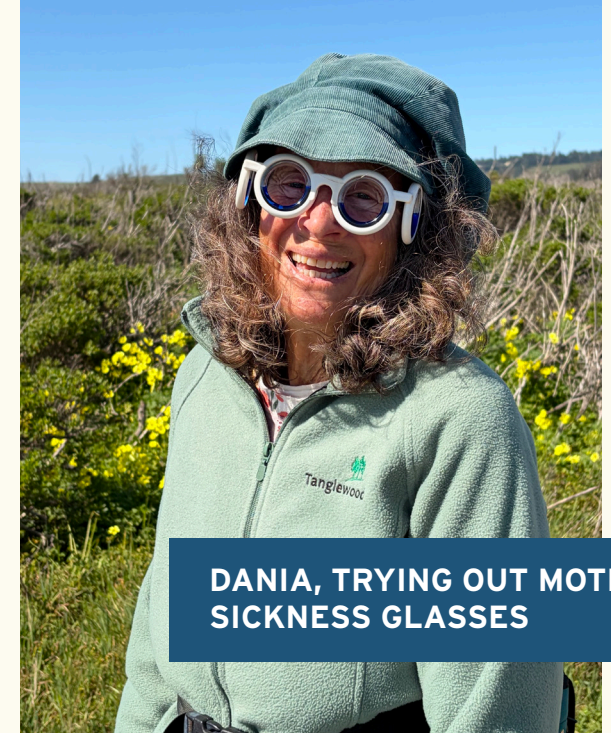
It is an honor to thank and share the story of Dania Moss, who has generously given to VeDA over the past several years. Her contributions have changed countless lives. Without people like Dania, VeDA wouldn't be here today. Dania, thank you.

Dania was 70, around her birthday, when vertigo first upended her life. She woke in the dark unable to tell up from down—terrified and alone—and was rushed to the hospital. These symptoms lingered for a month without a clear diagnosis or guidance. Years later, another severe episode. And again she experienced months of dizziness after her second COVID-19 vaccination. Despite visits to the emergency room, ENT, urgent care, and physical therapy over the course of years, she has never received an official vestibular diagnosis. That uncertainty is one of the most frightening aspects of her experience: not knowing when vertigo will strike, how long it will last, or what is causing it.

Dania remembers the feeling of relief when she first found VeDA and realized she wasn't alone. The resources and community she found in VeDA validated her experience in a way no clinician had. Where her healthcare providers often seemed unsure or unaware,

VeDA's information was clear, detailed, and deeply informed by both science and lived experience.

That validation is why Dania donates to VeDA. She gives so that people who wake up suddenly dizzy have somewhere to turn for information, community, and hope. Her support helps ensure VeDA's resources are there for others still searching for answers.



DANIA, TRYING OUT MOTION SICKNESS GLASSES



EVERY STEP COUNTS

STEPS-2-BALANCE MAY 17 - 23

STEPS-2-BALANCE (S2B) IS ABOUT TAKING A STEP TOWARD RECOVERY

When you are struggling with dizziness or imbalance, it's easy to become demoralized and feel like you'll never feel "normal" again. Recovery is a long road, and just thinking about taking one more step might feel like climbing a mountain - impossible.

By participating in S2B you are joining the global vestibular community in celebrating every win and milestone, large or small, because every step matters.

3 WAYS TO PARTICIPATE

1. Identify one "step" you can take in your vestibular recovery and plan to do that during the week of S2B.
2. Register and create a peer-to-peer fundraising page.
3. Organize or join an event in your local area.

WHAT COUNTS AS A "STEP"?

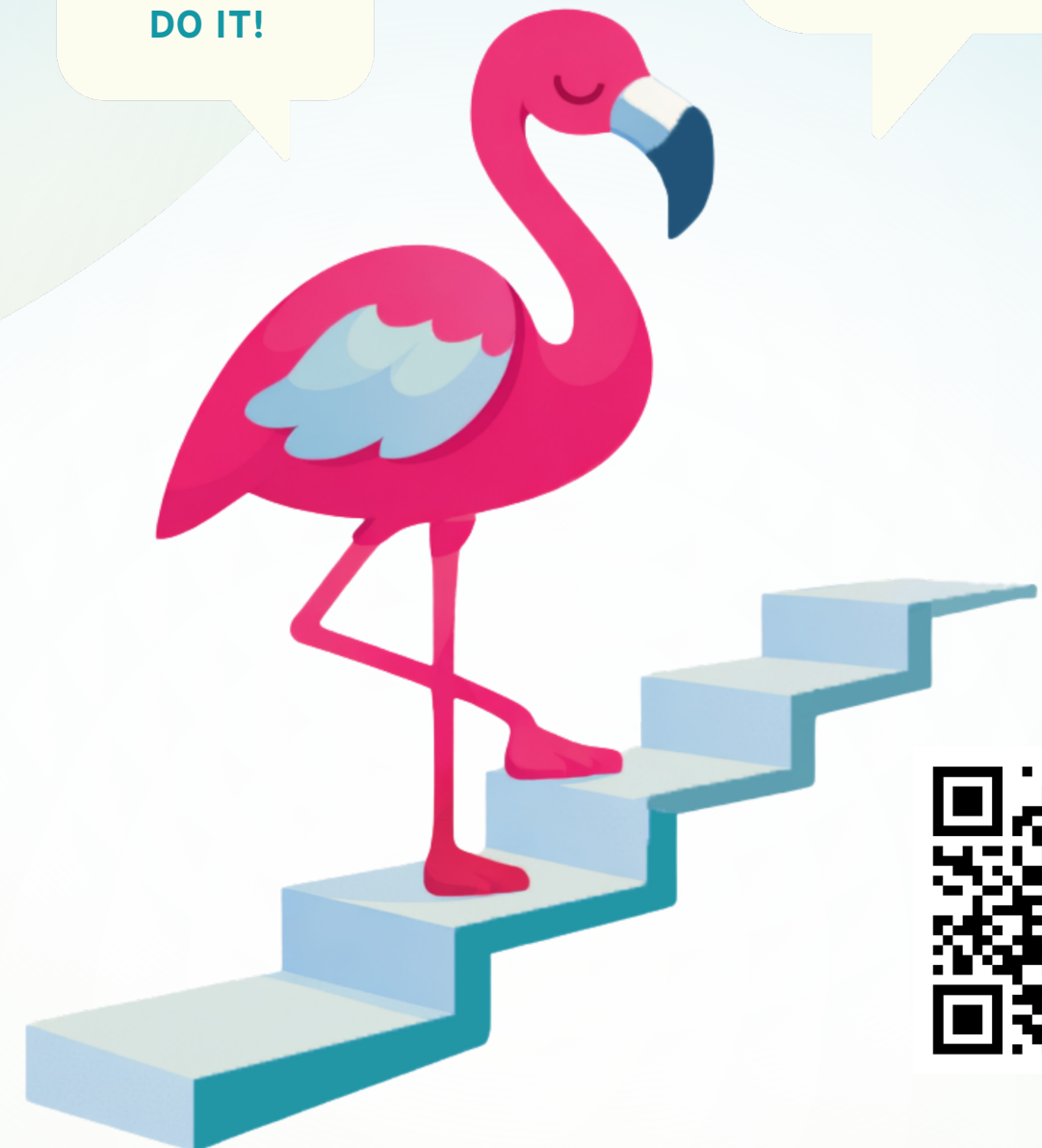
A "step" towards better balance will be different for every person. There is no wrong answer. The important thing is that you choose a "step" that will help you in your vestibular journey. Here are some ideas:

- Do one physical therapy exercise each day.
- Host a pop-up event to educate your community about balance awareness.
- Research which healthcare providers could help you get a diagnosis.
- Walk to your mailbox and back.

**YOU CAN
DO IT!**

**REGISTER AND
LEARN HOW YOU CAN
GET INVOLVED AT**

[VESTIBULAR.ORG/S2B](https://vestibular.org/s2b)



HOW THE BALANCE SYSTEM MAY CONTRIBUTE TO FEELING “UNREAL” OR DISCONNECTED

Research Summary

This research paper reviews decades of studies exploring an important but often overlooked question: Can problems with the vestibular (balance) system contribute to feelings of depersonalization and derealization?



Depersonalization refers to feeling detached from your own body or sense of self (for example, feeling “outside” yourself).

Derealization refers to feeling disconnected from the world around you, as if things don’t feel quite real.

The authors examined 23 studies involving more than 3,500 people, including both individuals with vestibular disorders (such as Ménière’s disease, vestibular neuritis, bilateral vestibular loss, PPPD, and vestibular migraine) and healthy volunteers who underwent artificial vestibular stimulation (for example, caloric testing or rotation).

FINDINGS

Across these studies, nearly 87% found that vestibular dysfunction or stimulation was associated with depersonalization and/or derealization symptoms.

A consistent finding was that people with dizziness or balance disorders report depersonalization and derealization far more often than people without dizziness. In some studies, over half of people with dizziness reported at least one depersonalization or derealization symptom. These experiences were not limited to psychiatric conditions as they frequently appeared alongside clearly defined inner-ear or balance problems.

Two factors showed up again and again as closely linked to these symptoms:

1. **Spatial disorientation** - difficulty knowing where your body is in space, feeling off-balance, or struggling to orient yourself.
2. **Anxiety** - especially anxiety related to movement, balance, or fear of symptoms.

POSSIBLE EXPLANATION

The authors propose that when vestibular signals from the inner ear are disrupted, the brain has trouble integrating balance information with vision, body sensation, and internal awareness. This mismatch can lead to a feeling that the body or the world is “off,” unfamiliar, or unreal.

Brain areas involved in this process include regions responsible for spatial awareness, self-perception, and emotional regulation, such as the temporoparietal junction, insula, hippocampus, and cingulate cortex.

CONNECTED RECOVERY

Importantly, the review also found that depersonalization and derealization symptoms often improve as vestibular function stabilizes or as patients recover, suggesting these experiences are not permanent personality changes but rather reversible responses to sensory



disruption.

In some cases, treatments or recovery from vestibular injury were associated with improvements in both balance and feelings of unreality.

KEY TAKEAWAY

Overall, this review supports a powerful and validating message for patients: feelings of depersonalization and derealization can be a direct consequence of vestibular dysfunction, not “just anxiety” or “all in your head.”

Understanding this connection may help clinicians better recognize these symptoms, reassure patients, and develop more effective, whole-person treatment approaches that address balance, spatial orientation, and emotional well-being together.

SOURCE Cento S, Gammeri R, Zavattaro C, Cirillo E, Serra H, Ricci R. The role of the vestibular system in depersonalization and derealization: Evidence from a systematic review. *Journal of Vestibular Research*. 2026;0(0). doi:10.1177/09574271251412707

HYPERVIGILANCE

THE SILENT AND PARADOXICAL EVIL IN VESTIBULAR DISORDERS

By Sam Tunney, M.D. Candidate
University of South Carolina School of
Medicine Columbia

People with a vestibular disorder often experience a sense of lost control and an inability to complete daily activities. In some instances, this loss of control also poses a danger to their physical well-being, such as when they are driving a car or walking down a flight of stairs.

When people become acutely aware of the sensations associated with an oncoming vestibular episode, they also become increasingly aware of



the circumstances in which these episodes occur, such as in settings with high-volume sound, uneven walkways, or quick head turns.

Unsurprisingly, these people actively work to limit or eliminate these triggers from their daily life and sometimes find themselves “on the lookout” for scenarios they strongly associate with their symptoms.

This phenomenon of increased avoidance and high cognitive effort in identifying nearby triggers is known in neuroscience as hypervigilance and is strongly associated with disorders involving the vestibular system¹.

WHEN FEAR BECOMES THE TRIGGER

Neuroscience suggests that physical symptoms are connected to what we’re aware of and afraid of. In simple terms, when two things happen together often, our brains start linking them. This is known in lay terms as “things that fire together, wire together.”²

This concept explains how neurons that perform completely different functions in the brain can become strongly associated with each other through synapse formation when they are consistently “fired



together.”²

Take hyperacusis (high sensitivity to sound), for example: The neurons that integrate the perception of heightened sound are not necessarily anatomically synapsed strongly with the neurons that perceive the symptoms of a vestibular episode or the fear associated with those episodes.

However, if a person initially suspects, rightly or wrongly, that their symptoms are directly triggered in settings involving loud noises, they will actively work to avoid these settings and, when unable to do so, will adopt a seemingly unavoidable fear response that occurs without the presence of, or could even directly lead to, a vestibular episode.

This creates a confusing cycle of fear that isn’t caused by the actual triggers

A PERSONAL REFLECTION

Karen Mizrach, longtime “Tips & Tricks” columnist for *On the Level*, shares a personal reflection on hypervigilance, plus she offers her quick tips at the end of this article.

About five years into my vestibular experience, I started seeing a mental health counselor to help me cope with my health challenges. As I explained my journey to him, and how I was managing, he repeatedly said, “You are hypervigilant.” Once he explained what that meant, I repeatedly said, “No, I’m just careful.” It took me a while to understand that being constantly on guard, always anticipating symptoms, and being overly cautious, was actually a huge part of my problem. What a stunning insight, and one I am still learning from.

He explained over and over that keeping my brain on constant alert for danger could intensify my symptoms, and not allow my nervous system to reset or relearn. Now I still catch myself being hypervigilant, but I can back off, relax and just breathe. I now don’t expect disaster at every moment and at times even forget all about my crazy vestibular system.

of their vestibular system but instead comes from how they see and connect their surroundings to their disorder.

Likewise, every time they find themselves in these settings, the neurons responsible for fear fire, and,



whether the symptoms occur or not, they become wired to the neurons that perceive that specific environment. From then on, that environment will almost always trigger a fear response, regardless of whether the symptoms follow.

IMPACT ON DAILY LIFE

Many people with a vestibular disorder cite the disruption of their daily life as the single most difficult symptom of these disorders. Ironically, hypervigilance in some people becomes even more disruptive than the disorder itself.

Not only will they find themselves actively avoiding activities or settings they once fully enjoyed, but they will do so with the misguided belief that not doing so would lead to more symptoms.

The main issue with this strategy is that it only reinforces the association between those conditions and their vestibular disorder, thereby strengthening the perceived threat associated with those activities or settings.

Even if a hypervigilant person were hypothetically “cured” of their vestibular disorder, their fear response would likely remain, as it was directly wired to the perception of the environment rather than the disorder itself.

HYPERVIGILANCE IN RESEARCH

This phenomenon was directly observed in orthopedic patients with “acute lower



back pain” who qualified as hypervigilant, developing into “chronic lower back pain” without any anatomic or physiologic changes.³ Researchers from this study were even able to “predict” which acute-state patients would develop into chronic-state solely based on their vigilance level.³

Although under-researched, the disorders of the vestibular system play by the same rules. It’s not necessarily about the disorders themselves; it’s the person’s fear of their symptoms that disrupts their daily life.

THE STOPLIGHT METHOD

There are many techniques utilized by neuroscience to alleviate hypervigilant behaviors. For example, using the “stoplight method,” a person identifies settings or stimuli they experience regularly. They then identify which settings and stimuli are “green lights” (unlikely to trigger symptoms), “yellow lights” (moderately likely to trigger symptoms), and “red lights”

KAREN'S QUICK TIPS

- 1. Expect to be ok sometimes** - There is a fine line between awareness of your body and constant monitoring of symptoms. Definitely know your body, and learn about your triggers, but accept that those situations will not always be a problem.
- 2. Show your brain there is other stuff going on in the world** - When you catch yourself obsessing on what could happen, slow your breathing and focus on something else. Notice your surroundings that are safe - like a beautiful view or interesting people or music that is upbeat/soothing, or try to think about an upcoming task (not vestibular related) and

(most likely to trigger symptoms). The key is not to eliminate red lights from their daily life; it is to recognize their existence and have the capacity to narrow down the instances in which vigilance is moderately warranted.

Additionally, patients who have completed this “categorization” process can strategically implement slow, incremental, and safe exposures to red lights, so they do not strengthen the association between those lights and their symptoms. In this method, hypervigilance serves as a tool for exposure therapy rather than a means of fear-based hyperfocus on their condition.

brainstorm options.

- 3. Talk to your brain** - “Hey, we’re going to be fine. This is safe. We’ve got this. Let’s just try this a different way and see what happens.”
- 4. Exercise** - Find a safe space - whether it’s in a chair, or a gym, or a pool, or on a track, get your body moving. Show your brain that you can move and get stronger. Instead of letting your brain convince you everything is scary and dangerous, flip it and tell your brain what’s what. Yes, it’s a bit of a mind game.
- 5.** And, as always, eat right, sleep well, spend time with other people, take care of your body and mind as best as you can.

FINAL THOUGHTS

Hypervigilance is often overlooked and unaccounted for. People with vestibular conditions are typically instructed to identify their triggers, but ironically, will sometimes feel they need to “live inside of” the constant awareness of those triggers. Recognizing the concept of hypervigilance and understanding when this methodology becomes destructive is paramount to the person’s ability to live a fulfilling, minimally limited life while taking decision-making power away from their disorder.

References available at vestibular.org/hypervigilance-ref

INVISIBLE SHADOWS

By Stana Peete

In the stillness where silence clings tight,
An unseen war brews out of sight,
A world that wobbles in a dizzying whirl,
Each step I take, a chasm unfurls.

The struggle whispers, yet it roars within,
Amidst a sea of faces, I'm lost in the din.
Every moment a trial, each breath a test,
As I navigate spaces that leave me
unrest.

Screens flicker and pulse, a
seductive glow,
But they amplify chaos, pulling me low.
Harsh lights pierce like daggers,
cutting the air,
In this tangled web, clarity's rare.

Crowds rush around me, a storm left unchecked,
While I seek solid ground, feeling circumspect.
Uneven terrain jeers with each faltering stride,
A dance with uncertainty, where I must confide.

Scents swirl in the air, sharp and intense,
Overwhelming and heavy, they steal my defense.
Each breath a reminder of battles I wage,
In a realm that can't see my invisible cage.

Yet from this struggle, a spark of resolve,
A quiet strength blooms, as darkness dissolves.
Though unseen, my journey weaves threads of grace,
I search for the calm in this frantic race.

So here's to the fighters, though hidden from view,
To those who endure, who rise and push through.
In a world that may overlook the storms that we bear,
We carry our light, our courage laid bare.

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