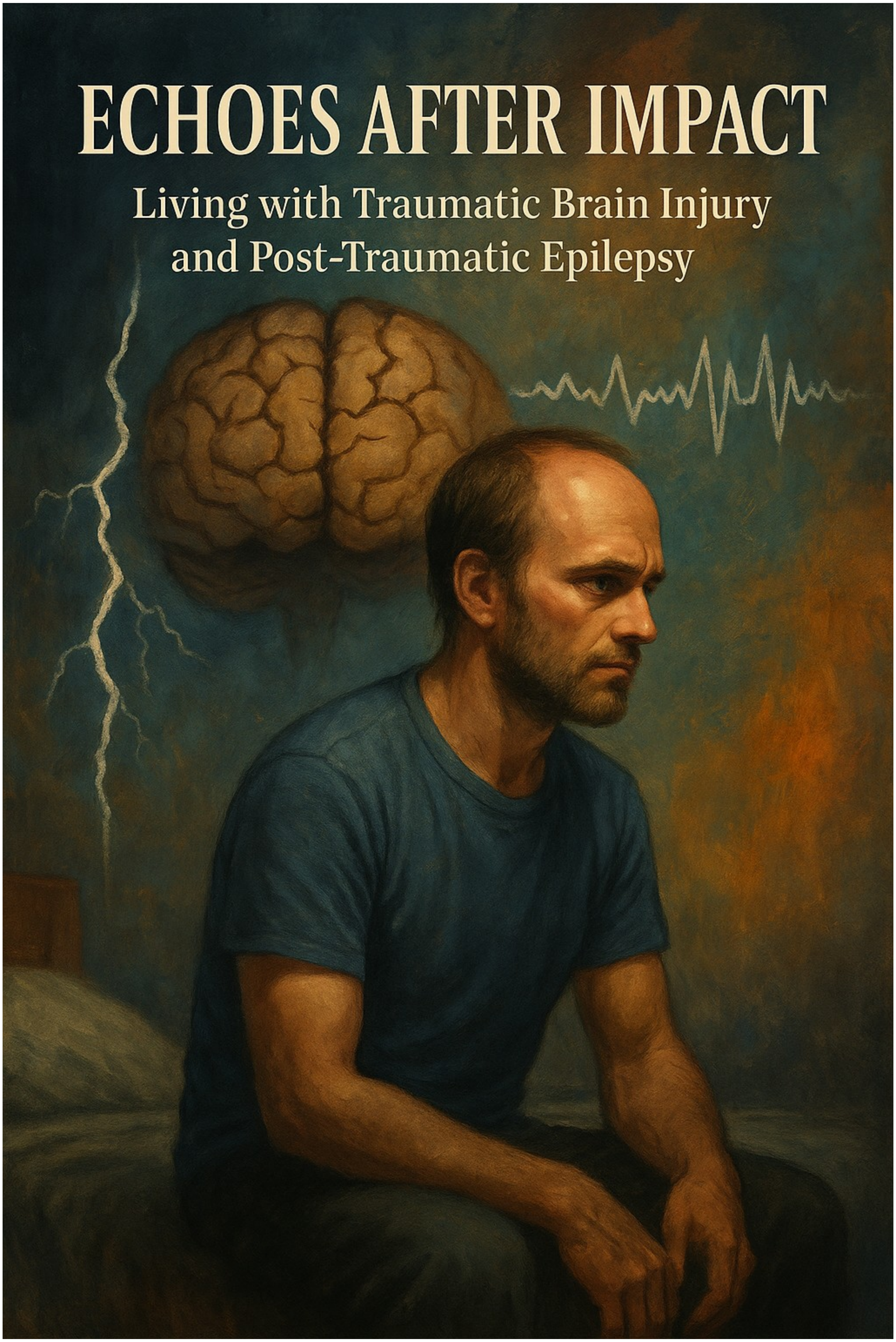
ECHOES AFTER IMPACT

Living with Traumatic Brain Injury and Post-Traumatic Epilepsy



Introduction

> "At 26 years old, I was thrown through the sunroof of an SUV during a violent rollover crash. I don't remember the impact. I don't even remember the months prior. But I've lived with its consequences every moment since."

In 2011, a car accident nearly took my life and irreversibly changed its course. I sustained a traumatic brain injury (TBI) along with a crushed vertebra and other injuries. I woke up in a Dayton, Ohio hospital with no memory of the crash itself – a blank space where months of my life should have been. Over a decade later, I am still grappling with the echo of that impact. My motivation in writing this is simple: to help others understand the long-term reality faced by TBI survivors who, like me, develop post-traumatic epilepsy. **Traumatic brain injury is not just an event but "a disease process" with chronic effects**, and its aftermath is often misunderstood. Motor vehicle accidents like mine are a major cause of severe TBIs – they account for about 17% of non-fatal TBIs and are the leading cause of TBI-related deaths in the U.S.. I share my story not for sympathy, but so that others might feel seen, understood, and better supported.

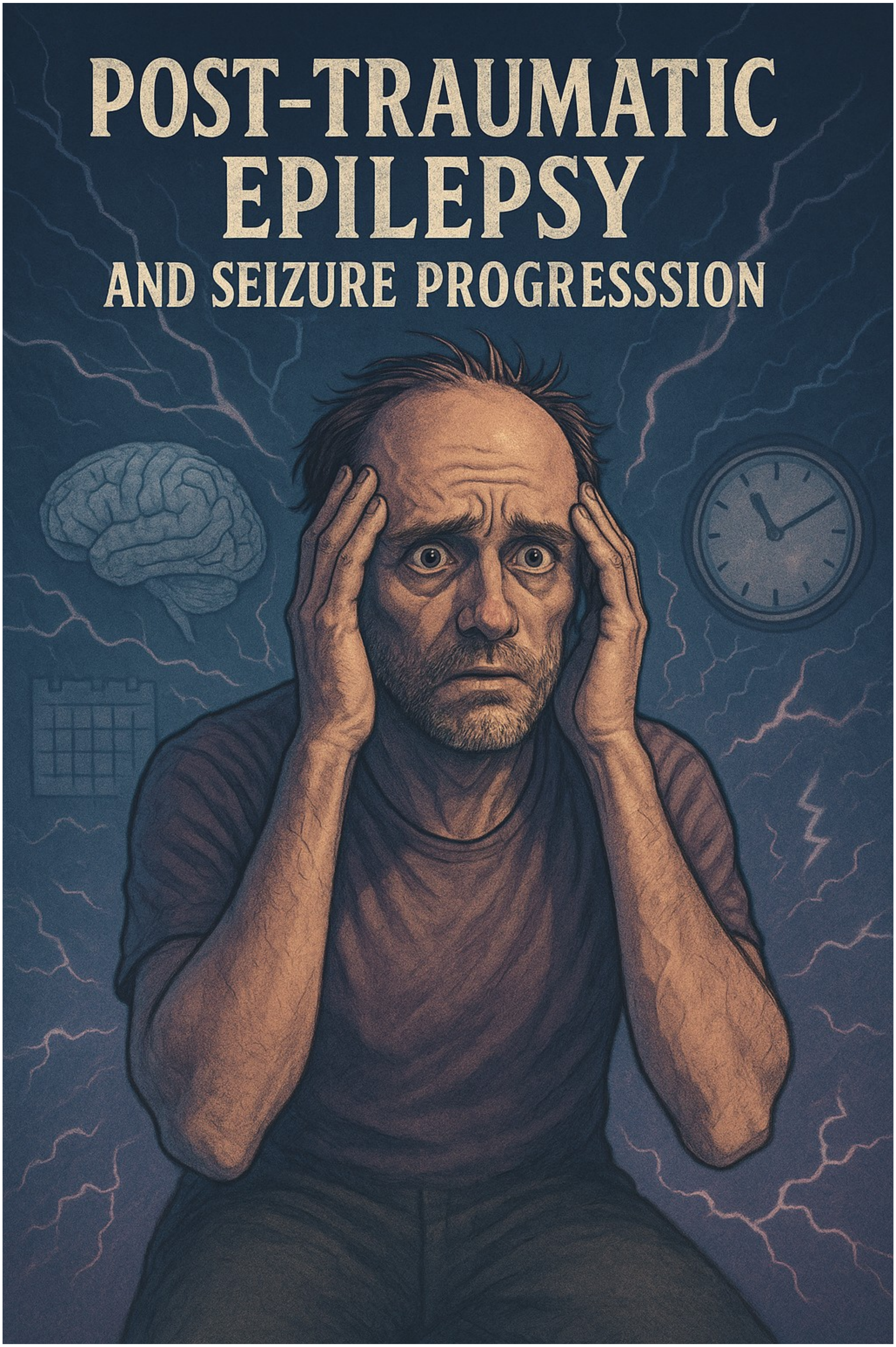
THE ACCIDENT AND IMMEDIATE INJURIES

On a summer night in 2011, my life changed in an instant. My friend's SUV swerved off the road and rolled over multiple times. According to the police report and witnesses, I was ejected through the sunroof and landed several yards away. Emergency responders found me unconscious and barely breathing. I was rushed to a trauma center in Dayton, OH, where scans revealed I had fractured and **dislocated vertebrae in my spine, sustained a severe TBI, and had internal injuries.** The immediate outlook was uncertain: I underwent surgery to stabilize my spine and relieve brain swelling, then spent days in the intensive care unit. I remained in post-traumatic amnesia for about a week – I remember nothing of the ICU or the accident itself, a merciful blank in an otherwise harrowing story.

Such crashes are all too common in TBI statistics. The Centers for Disease Control and Prevention (CDC) report that **motor vehicle crashes are among the top causes of TBIs and the single leading cause of TBI-related fatalities**. Thanks to excellent acute care, I beat the odds by surviving. But survival was only the beginning of a new struggle. In the aftermath of my injury, I had to relearn basic tasks – how to walk steadily, how to concentrate past the fog in my head – all while managing pain from my spinal fractures and headaches from the brain injury. Doctors warned my family that **TBI can have lasting cognitive, emotional, and physical effects** long after the bones mend. I was hopeful I could beat those odds too. At 26, I was young and determined; I threw myself into rehabilitation. With time, my cuts and bruises healed, the bone fractures fused, and outwardly I began to look "normal" again. Nobody could see the damage hidden inside my skull. Unfortunately, the hidden damage would make itself known in a devastating way: through seizures.

Traumatic brain injuries often leave a lingering “electrical scar” on the brain that can lead to epilepsy. Statistically, I later learned, I was far from alone in developing seizures after a TBI. **About 1 in 50 people who sustain a traumatic brain injury will go on to develop post-traumatic epilepsy (PTE)**, even if their injury initially seemed to heal. The risk is even higher with severe head injuries like mine. In fact, longitudinal studies have found that **approximately 10–16% of patients with severe TBI develop epilepsy over the decades following the injury**. (By comparison, mild TBIs carry only around a 2% long-term risk.) In other words, the more violent the brain trauma, the greater the chance that years later the survivor may start having unprovoked seizures. This is the reality that was waiting for me down the road, even as I “recovered” from the accident. The seeds of epilepsy were likely planted in my brain the moment I sustained the TBI – but they would not sprout until much later. The stage was set for a second health crisis: **post-traumatic epilepsy, a lurking complication that can remain latent for months or years after the initial trauma**.

POST-TRAUMATIC EPILEPSY
AND SEIZURE PROGRESSSION



Timeline and risk factors for developing post-traumatic epilepsy (PTE) after TBI. In general, about 2% of TBI survivors (1 in 50) develop epilepsy as a direct result of their brain injury. The risk is highest in more severe injuries and within the first few years post-trauma, but ***PTE may not appear until many years after the initial injury*** *in some cases. Early seizures (within the first week) are a separate phenomenon; late unprovoked seizures that define PTE can begin long after hospital discharge.*

I made it through 2011 with a long hospitalization and rigorous rehab, and through 2012 as well, slowly rebuilding my life. Then in 2013 – **two years after the wreck** – the latent threat became reality. I experienced my first epileptic seizure. It struck out of the blue: I was at home alone when I suddenly lost about ten minutes of time. I "came to" on the floor, confused, with a bitten tongue and muscles so sore it felt like I had run a marathon. I had no idea what had happened, and neither did my family. In hindsight, these were classic signs of a generalized tonic-clonic seizure (what used to be called a grand mal seizure). But at the time, neither I nor my loved ones recognized it. We thought maybe I'd fainted from stress or low blood sugar. The possibility of **epilepsy emerging *years* after a head injury** seemed bizarre. Yet that is precisely how post-traumatic epilepsy often behaves – lying dormant and then emerging unpredictably. Neurology literature confirms that **the risk of PTE is greatest within the first couple of years after a TBI and then gradually declines, but PTE can indeed begin many years later**. In fact, roughly **80% of people who will develop PTE have their first seizure within two years of the trauma, and about 20% have the first seizure after that window**. I turned out to be one of the latter group – the slow-blooming 20%.

My early seizures were infrequent and thus poorly understood. After that first major blackout, I had no more big convulsions for a while. Instead, I had strange episodes that I downplayed or misinterpreted: sudden moments of déjà vu, or an odd sense of **"lost time"** where I couldn't recall what I had just been doing. At the time, I wrote these off as stress or normal memory lapses. In reality, I was likely experiencing focal impaired-awareness seizures (formerly called complex partial seizures) originating from the damaged area of my brain. **Most seizures in post-traumatic epilepsy are focal in onset**, meaning they start in one injured region and sometimes spread to affect the whole brain. Looking back, those "glitches" in my memory were probably brief seizures where I was essentially on autopilot for 30 seconds, and then consciousness "clicked" back in. But because I didn't collapse or shake, I (and my doctors at the time) did not immediately recognize them as seizures.

Over the next few years, my seizures increased in frequency and intensity. What began as a few spells per year progressed into *dozens* of seizures per year. By my early 30s, I was having seizures nearly every month, sometimes clusters of them. **Stress became a major trigger** – high levels of anxiety or lack of sleep would all but guarantee I'd have a seizure within days. This is consistent with what many epilepsy patients report: **physical and emotional stress, fatigue, and poor sleep can lower the brain's seizure threshold**. Unfortunately, living with epilepsy *creates* stress, forming a vicious cycle. My seizures also became more varied. While many were still the sort of "zone out" focal seizures that only those close to me could notice, I also experienced a handful of full-blown generalized seizures with convulsions. Nothing is more terrifying than regaining consciousness on the floor, disoriented, with concerned faces hovering above you – knowing that your own brain has betrayed you again without warning.

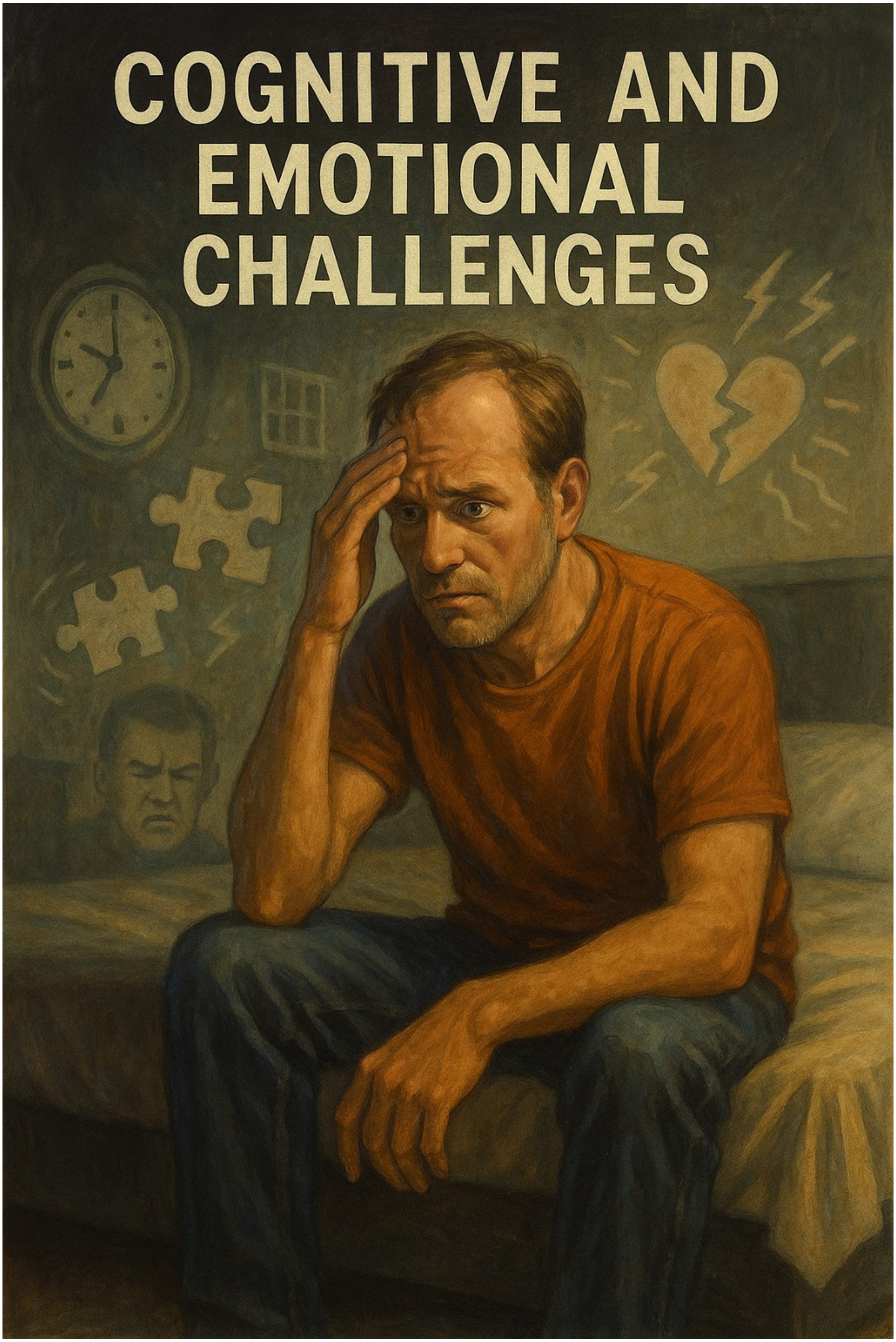
Post-traumatic epilepsy (PTE) often has a long and unpredictable course. In some people, it remains mild or infrequent; in others (like me), it tends to worsen over time or resist treatment. The seizures have tangible impacts on daily life: I've suffered **memory gaps, confusion, and mood swings around the time of seizures**. After a seizure, I experience a postictal phase – essentially a mental fog and exhaustion that can last hours or days. It's not just the moments of the seizures themselves that steal time from my life, but the recovery afterward and the constant fear of the next episode. **Research shows that PTE can affect memory, executive function, and behavior**; for example, injuries to the frontal or temporal lobes (common in TBI) can impair short-term memory and emotional regulation. I sometimes describe my memory as "glitchy" – I can remember obscure details from years ago, yet I'll forget an important conversation from yesterday. It's not continuous amnesia, but spotty, like Swiss cheese. Neuropsychologists even use the term "*Swiss cheese memory*" for this phenomenon: TBI survivors can have many holes in their recall, where information just falls through and is lost.

Perhaps most disruptive is the uncertainty. I never know when a seizure will strike. **Imagine carrying on with your day, and at any moment you might suddenly "lose" a few minutes – or worse, wake up on the ground injured.** That unpredictability is one of the hardest aspects of PTE. It takes a psychological toll, which I'll discuss more in the next section. I coped by avoiding potential dangers: I gave up driving for long periods, I shower only when someone else is home (for fear of blacking out in the bathroom), and I developed an almost hyper-vigilant awareness of my body's signals. Despite all precautions, epilepsy often laughs in the face of our plans – seizures come when they want, not when it's convenient.

It’s worth noting that my trajectory – a seizure disorder emerging long after the initial injury, confusing symptoms, then a progression in frequency – is not unique. **Case studies abound of TBI survivors who seemed fine for months or years, only to be blindsided by late-onset seizures.** For instance, one veteran of the Iraq War suffered a severe combat-related TBI and had no seizures during early recovery, but then *“the onset of epilepsy… months into [his] recovery process” suddenly erased much of his hard-won progress**. His wife described how shocking it was to have him survive a bullet wound to the head, only to later be fighting debilitating seizures that brought new challenges. Another individual shared his experience in a Q&A forum: he **fully recovered from a 2003 head injury, only to experience his first grand mal seizure seven years later, in 2010, seemingly out of nowhere**. His doctors initially thought it was a one-time event due to alcohol and sleep medication lowering his seizure threshold, but then he had another seizure at work, triggered by extreme fatigue and stress. Stories like these underscore a critical point: PTE may *emerge long after* the trauma, making diagnosis and treatment a complex, delayed battle.

Living with PTE means living with a foot in two worlds: the world of brain injury and the world of epilepsy. I am a brain injury survivor **and** an epilepsy patient, each condition layering on top of the other. In the next sections, I will delve into how this combination has affected my cognition, emotions, and interactions with the medical system and society.

COGNITIVE AND EMOTIONAL CHALLENGES



If a brain injury and epilepsy individually can wreak havoc on one's mental state, their combination – post-traumatic epilepsy – presents a unique challenge. My **memory is fragmented** in ways that are hard to explain to someone who hasn't lived it. I mentioned "Swiss cheese memory" above; this metaphor resonated with me the first time I heard it. One caregiver described it well: *"Just like Swiss cheese, there may be a lot of holes in the memory of a traumatic brain injury survivor"*. I have large gaps in recollecting the year or so after my accident. Even beyond that, I experience unusual memory lapses in day-to-day life. I may be telling a story and suddenly I can't remember a key event, or I'll walk into a store and forget why I'm there – beyond normal forgetfulness. On some days my mind feels sharp; on others it's like someone sliced random holes out of my recent memories. This isn't *Hollywood* amnesia where I've forgotten my name or childhood; it's more subtle and frustrating, a patchy inconsistency. Neurologists explained to me that my initial TBI damaged some of the neural networks involved in forming and retrieving memories. Each significant seizure could also cause "aftershocks" that jolt the brain's wiring, contributing to cognitive difficulties. Indeed, **each convulsive seizure can temporarily impair memory and cognitive function**, and repeated seizures have cumulative effects on attention and executive function.

Emotionally, I have struggled with periods of depression, anxiety, and irritability that I *never* experienced before the injury. Part of it is a direct result of the brain trauma – after all, **TBI can injure the limbic system and frontal lobes, the very areas that regulate mood and impulses**. Another part is situational: living with a seizure disorder is inherently stressful and isolating. I sometimes feel like **a ticking time bomb**, which makes it hard to relax or feel "normal." My fuse became shorter after the accident; I would snap in anger over minor things or become overwhelmed by frustration more easily than before. This kind of **emotional dysregulation is a known consequence of brain injuries**, which can leave survivors prone to irritability, aggression, or rapid mood swings. In my case, I have to contend with not just the personality changes from the TBI, but also the mood-disturbing effects of seizures and anti-epileptic medications. It's a perfect storm in the brain.

One particularly frightening symptom I developed is intense **anxiety and panic**, especially in the aftermath of seizures. After a big seizure, I often wake up in a confused, combative state – heart pounding, not knowing where I am, sometimes even lashing out or yelling. This post-seizure agitation is beyond my control, but it's distressing for everyone around me. Over time, I've also begun having panic attacks *anticipating* seizures or in situations where I feel unsafe. Crowded, noisy environments can send my anxiety skyrocketing because my brain, now sensitized by trauma, easily becomes overstimulated. It's as if the fight-or-flight switch in my limbic system is hair-triggered. **Neuropsychiatric effects like anxiety and depression frequently accompany post-TBI epilepsy**, and I have experienced both in full force. I have sought therapy and medication to help with these issues, with mixed results.

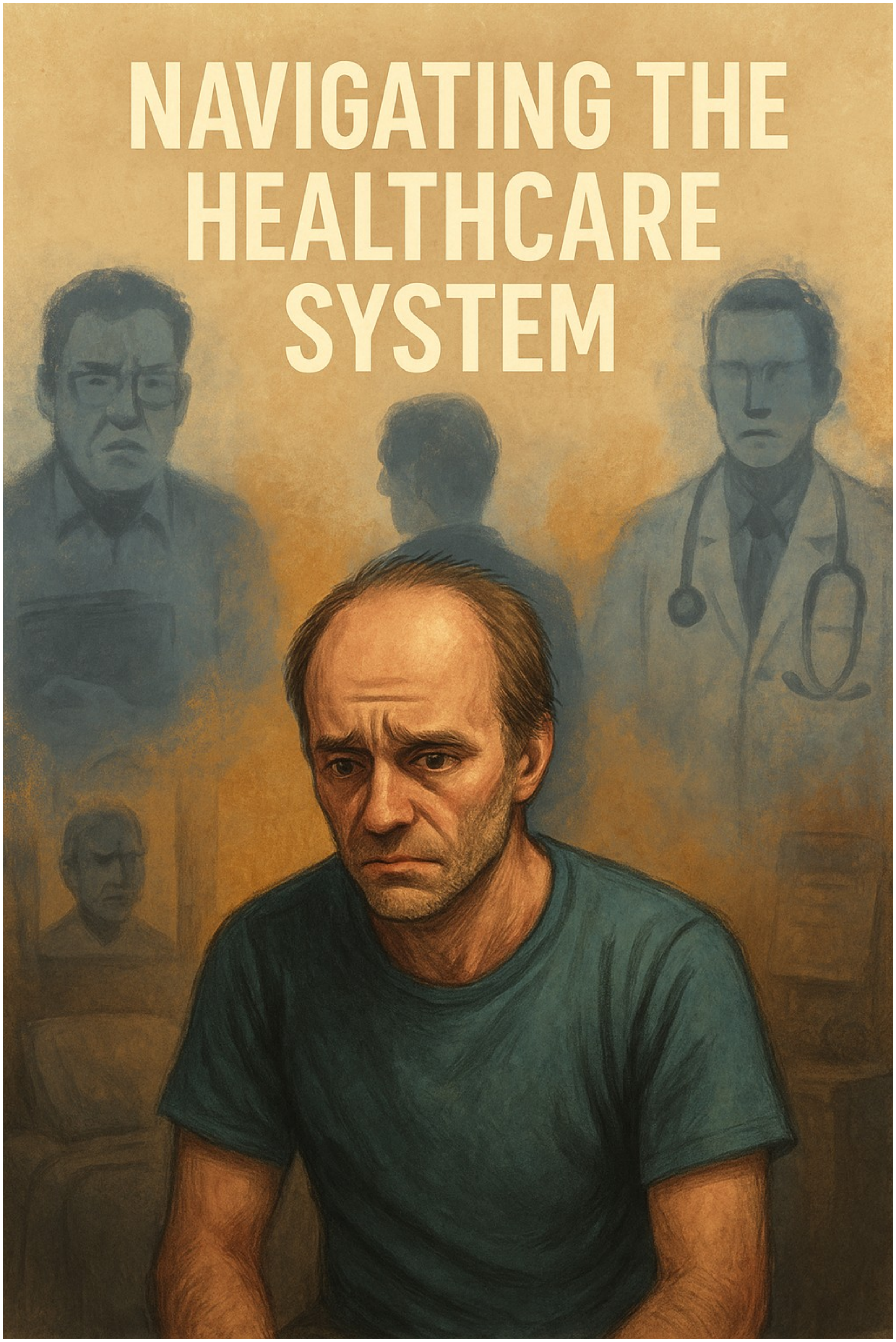
Beyond the internal struggles of memory and mood, there are **practical safety concerns** that dominate my life. I mentioned I don't shower or swim alone due to fear of having a seizure in water. I also have to be careful around heights (even simple ladders) and open flames (like a gas stove) – any scenario where losing consciousness could be fatal. I've put safeguards in place: I wear a medical alert bracelet at all times, I have taught close friends and coworkers how to perform seizure first aid, and I use technology like smartwatches that can detect falls and alert emergency contacts. These measures help, but they also constantly remind me that I'm not like everybody else. There is an emotional burden to always being *on guard*. A day with no incidents isn't a day of true peace; it's a day spent quietly scanning my body for warning signs, living under a Sword of Damocles that might drop without notice.

Perhaps **the hardest part is the loss of trust in my own brain**. I used to take for granted that my mind would do what I needed it to. Now, I know that my brain can overwhelm me with anger, or erase my memories, or shut down entirely in a seizure – all without my consent. This realization has at times led me to dark places emotionally. It's not uncommon for those with PTE or other refractory epilepsies to experience a kind of mourning for their pre-injury self. I certainly went through (and still go through) waves of grief and anger at what was taken from me. I grieve the *old me* who was carefree, who didn't need to worry about injuring herself during a simple grocery trip. As one brain injury advocate put it, *"Many people who have a brain injury talk about the person they were before the brain injury and the person they are now."* I resonate strongly with that sentiment.

Despite these challenges, I want to emphasize that it's not all despair. Over the years, I've adapted and found strengths too. I've become more patient with myself (out of necessity). I celebrate small victories that others might overlook. And I've discovered a resilience I never knew I had. One fellow survivor of TBI and epilepsy, **María, described waking up from seizures feeling utterly exhausted and lost, yet ultimately she learned to live again**. She wrote about how *"I hated that feeling of being lost, feeling so weak, and making people worried"* every time a seizure happened. But with time, María got on effective treatment and has been seizure-free for years now, regaining confidence to drive and even ride roller coasters again. Her words mirror my own feelings: I, too, have felt weak and a burden on loved ones when my brain failed me. Yet here I am, still fighting. In María's words, *"I have learned to work hard and be stronger than I ever thought… that strength is what has made me successful in my fight with epilepsy."*

Not every day is successful for me yet – I still have seizures to conquer – but I hold onto that mindset. I've come to realize that surviving and living with this condition *is* an accomplishment in itself. Next, I will discuss the external challenges: dealing with the healthcare system and society at large, which often pose their own difficulties on top of the medical issues.

NAVIGATING THE HEALTHCARE SYSTEM



Finding proper treatment and support for post-traumatic epilepsy has been, in many ways, an ordeal of its own. In the early years after my injury, my interactions with doctors were a mixed bag. The trauma surgeons and rehabilitation physicians who saved my life and got me walking again were incredible. However, once seizures entered the picture, I found myself mainly in the care of neurologists – and this is where I often felt **lost in the system**. Post-traumatic epilepsy doesn't always fit neatly into the usual categories of epilepsy, and I quickly discovered that not all neurologists are well-versed in the long-tail consequences of TBIs.

One major challenge was simply **getting a clear diagnosis and effective treatment plan.** My first neurologist was skeptical that my initial episodes were seizures at all. Standard tests like EEGs (electroencephalograms) and MRIs came back without dramatic findings – which is not unusual, since PTE often originates from deep or scarred brain tissue that might not show up on surface EEG leads. In fact, **cases have been documented where patients had normal EEG results and thus "many doctors dismissed an epilepsy diagnosis," only later to find that the seizures were originating too deep in the brain for EEG to detect**. I suspect my early focal seizures were similarly missed. For a while I was in a diagnostic limbo, told to "reduce stress and rest more," as if my episodes were psychosomatic. It was deeply validating (if unfortunate) when I finally had a full tonic-clonic seizure in front of witnesses – only then did the medical team unanimously conclude, "Yes, this is epilepsy." I was formally diagnosed with focal epilepsy in 2014 and started on anti-seizure medication.

Finding the right medication turned out to be another lengthy trial-and-error process. Over the past decade, I have been prescribed nearly every major anti-epileptic drug (AED) on the market: phenytoin, levetiracetam, lamotrigine, topiramate, and others, alone or in combinations. Each came with side effects, and unfortunately none have completely controlled my seizures. This isn't surprising in hindsight, as research shows that **post-traumatic epilepsy is frequently resistant to medications**. One study found about **20% of PTE patients eventually developed drug-resistant epilepsy**, and other data indicate PTE is more likely to be refractory compared to non-trauma-related epilepsy (in one analysis, 45% of people with PTE had drug-resistant seizures versus 33% in other epilepsies). I have so far fallen into that stubborn category – despite high doses and combinations of drugs, I continue to have breakthrough seizures. The side effects have at times been brutal: one drug gave me constant brain fog and word-finding difficulty, another made me irritable and depressed, and yet another caused tremors in my hands. Managing epilepsy often means balancing seizure reduction with tolerable quality of life, and it can take years to strike that balance. I work closely with an epileptologist now (a seizure specialist), and we haven't given up. We're currently exploring the possibility of epilepsy surgery or neuromodulation devices, which have been used in some severe PTE cases. But those options come with big risks and require extensive evaluation. It astonishes me that we have *no* medication that can definitively prevent or cure post-traumatic epilepsy – a sobering reminder of how much research is still needed.

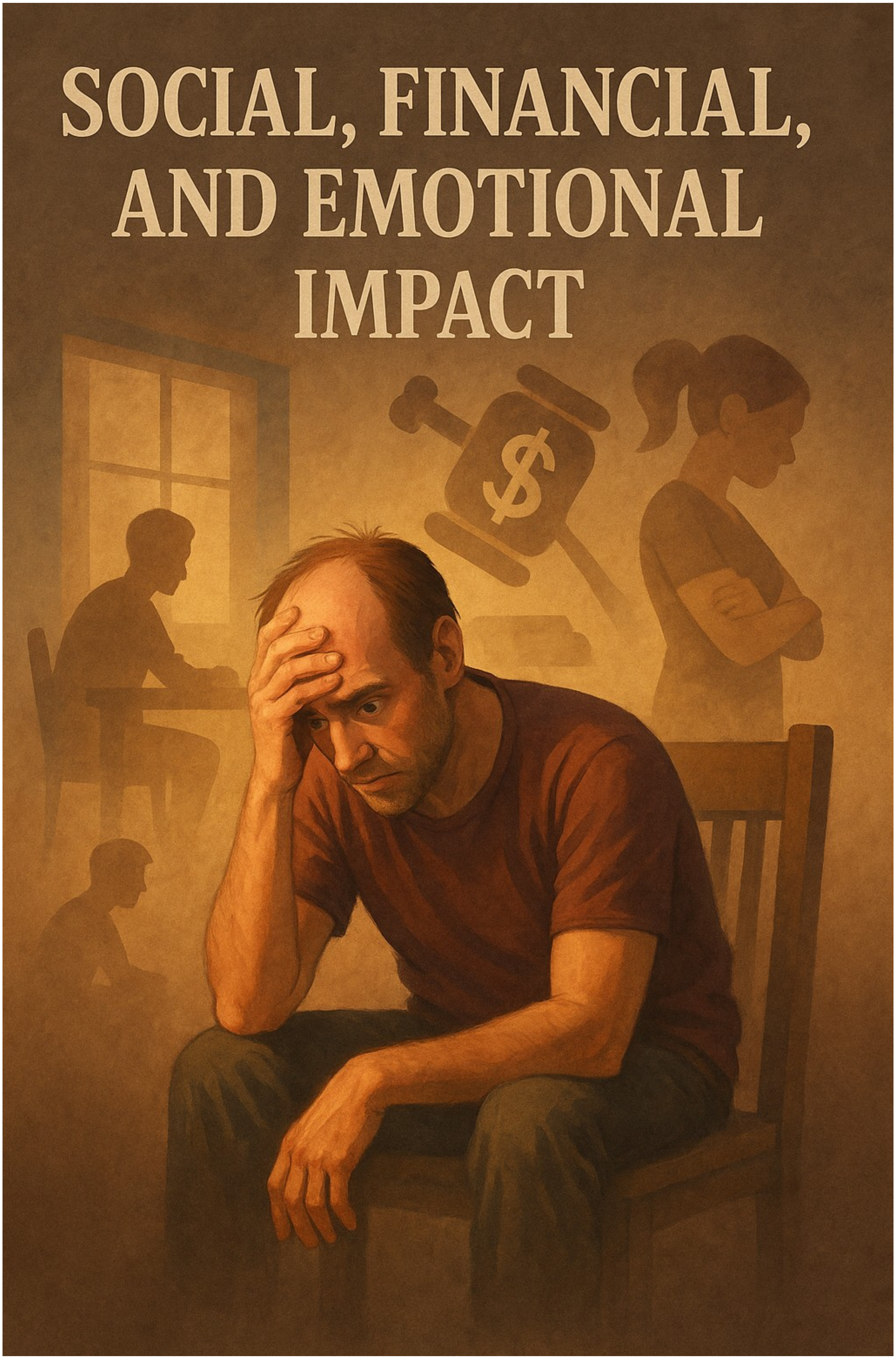
Another frustration has been the **fragmented care approach** to my condition. Too often, doctors looked at one piece of the puzzle (say, the seizures) but ignored others (like my cognitive and emotional symptoms). For example, when I brought up memory problems or fatigue to my neurologist, I was told to ask my primary care doctor or a neuropsychologist, each of whom in turn referred me elsewhere. It sometimes felt like no one owned the "big picture" of my case. This is a common complaint among TBI survivors: once the acute trauma care and rehab are over, we're left to navigate a labyrinthine healthcare system on our own. I have personally experienced being **bounced between specialists** – a psychiatrist for depression, a neurologist for seizures, an endocrinologist for hormone imbalances linked to the TBI, etc. Each siloed specialist sees their piece, but who is addressing *me as a whole person*? Holistic, patient-centered care in neurology is unfortunately rare, as the system tends to compartmentalize. I long for a more integrated approach, where a multidisciplinary team could coordinate and truly listen to all my concerns.

Many survivors of post-traumatic epilepsy also report feeling **dismissed or "gaslit" by medical professionals** at times. I've had doctors (thankfully a minority) imply that I was exaggerating my symptoms or that if tests looked okay, then everything must be fine. This is incredibly demoralizing. One extreme example from the epilepsy community involved an ER doctor telling a patient "you're not epileptic" simply because their tests were normal and the doctor was undereducated about TBI-related seizures. While I haven't encountered that exact scenario, I have felt the sting of skepticism in doctors' offices when describing my aura symptoms or memory issues. It's as if because these symptoms are invisible and subjective, they carry less weight. **Invisible disabilities like brain injury and epilepsy are frequently misunderstood** – if you look young and healthy, some assume you must be "making it up" or that it's "not that bad." This couldn't be further from the truth, and it creates a barrier between patients and providers that harms trust.

One particular gap in the system I want to highlight is the lack of mental health support woven into neurological care. The emotional and psychiatric dimensions of post-TBI life (like depression, anxiety, PTSD) are often underdiagnosed and undertreated. In my case, I developed clear signs of post-traumatic stress (hypervigilance, nightmares about the accident) and mood disorder symptoms, but it took years before any provider screened me for PTSD or depression. As one story noted, a patient was *"easily frightened by loud noises — a symptom of PTSD for which she wouldn't receive a diagnosis for many years"* after her brain injury. I can relate; it was nearly 10 years post-accident that I finally saw a neuropsychiatrist who said, "No wonder you feel on edge – you very likely have PTSD from the crash on top of everything else." Getting that diagnosis so late felt like another example of the system's tunnel vision. We treat the visible injury (the broken bones, the seizures) but can miss the psychological trauma simmering underneath.

In summary, navigating the healthcare system with a traumatic brain injury and subsequent epilepsy has been like walking a tightrope. I've encountered brilliant, compassionate clinicians who went above and beyond for me, and I've also hit walls of indifference or ignorance. **I've learned the importance of self-advocacy** – keeping detailed logs of my seizures and symptoms, educating myself on the latest research, and sometimes pushing back if I feel my concerns are being downplayed. Not every patient is able to advocate for themselves, especially when cognitively impaired, which is why it's so crucial that the medical community improves how it manages these cases. TBI is **not** a one-and-done event; it is a chronic condition that requires long-term, nuanced care. Post-traumatic epilepsy is a prime example of that, emerging down the line and demanding ongoing attention. I consider myself fortunate to now have a knowledgeable care team, but it shouldn't be about luck or persistence – every patient deserves that standard of care from the start.

SOCIAL, FINANCIAL, AND EMOTIONAL IMPACT



The effects of my condition extend far beyond the doctor's office. **Living with a brain injury and epilepsy has profoundly impacted my social life, career, and family.** In many ways, it is an *invisible disability*. On the surface I might look fine – I can walk, talk, and carry on with daily activities. But unseen cognitive issues and the ever-present risk of seizures create limitations that outsiders often don't grasp. **"Brain injury is called an invisible disability because there are often no visible physical signs of injury,"** as one expert explains. "*Because the injury can't be seen, people with a brain injury can be misunderstood and treated differently.*" I have experienced this misunderstanding countless times. For example, when I've had to disclose my condition to an employer or professor, the initial response is sometimes skepticism or even subtle discrimination. I've heard comments like, "Well, you look fine to me," or "Everyone forgets things, you just need to try harder." Such remarks miss the reality that my brain operates differently now. **People may assume I'm less capable or even question the legitimacy of my disability** because they can't see it. This kind of stigma adds an extra layer of stress and isolation.

Employment and financial stability have been major casualties of my condition. Before the accident, I was an active young adult with a budding career in my field. After the accident and the onset of PTE, working became challenging. In the early years, my cognitive fatigue and memory problems made full-time work difficult – I had to reduce my hours significantly. Later, as seizures increased, so did absenteeism. There were days I couldn't come in because I'd had a seizure the night before and was too disoriented the next day. On a few occasions, I had seizures at work; imagine the embarrassment and fear of waking up on your office floor with coworkers around you. While my colleagues were kind, it was clear that my reliability as an employee was impacted. Over time, I had to switch to less demanding jobs and ultimately part-time consulting from home, which meant a big pay cut and loss of career momentum. Unfortunately, this too is a common outcome: studies show **TBI survivors face much higher rates of unemployment and underemployment** than the general population. In one analysis, about 60% of working-age adults with moderate-severe TBI were unemployed one year after their injury. I count myself lucky that I can still work at all, even if not at my full capacity. Financially, the cost of medications, frequent doctor visits, and the lack of full-time income have been burdensome. I did eventually qualify for certain disability benefits, but those are modest. My family has also shouldered expenses to ensure I have what I need (for example, modifying my living environment for safety). The monetary cost of a brain injury is huge, but the emotional cost is perhaps even greater.

Socially, I went from being an extrovert who loved going out with friends to someone who often stays home. **Epilepsy imposed certain social restrictions:** I cannot drink alcohol (it interacts badly with meds and can trigger seizures), I shouldn't stay out late (sleep deprivation is a trigger), and loud flashing environments like clubs are overwhelming to my brain now. As a result, I gradually withdrew from many social engagements. Friends tried to be understanding, but over time some drifted away when I kept declining invitations. It's hard for people in their 20s or 30s to consistently accommodate a friend who has to leave early or who might have a medical emergency at any moment. I don't blame them entirely – it's just a different reality. I've been incredibly fortunate to have a core group of supportive friends and, most importantly, a loving family. They have adjusted alongside me. My parents, for example, had to accept their adult son was now someone who might need periodic caregiving. **Family members often become caregivers for TBI survivors, which can strain relationships and alter family dynamics**. In my case, my parents and siblings all educated themselves about seizures and stepped up to help in various ways (driving me to appointments when I couldn't drive, staying with me during bad periods, etc.). I know it has not been easy on them. There have been tense moments and arguments borne of stress – like when I chafed at my parents' protective instincts or when they grew frustrated at the situation they couldn't "fix." Yet, their presence has been literally lifesaving on occasions (for instance, my mother was with me during a seizure where I stopped breathing and she kept my airway open). Many others are not so lucky to have that support. Sadly, brain injuries can **lead to broken relationships, divorce, or family separations** if the proper supports aren't in place. I personally know of fellow survivors whose spouses left because they "didn't sign up for this," or who lost custody of children because the courts viewed them as incapable due to their disability. These social ripple effects are profound and underappreciated.

Isolation has been another challenge. There's a saying in the brain injury community: *"Brain injury is a club you never wanted to join."* The same could be said of epilepsy. Finding people who understand has been crucial for me. I started attending a local support group for people with epilepsy, and I connected online with others who have TBI-induced seizures. Hearing their stories, I realized I wasn't alone in feeling the way I do. One person wrote anonymously about his PTE: *"I have seizures really bad now – day and night. I'm a wreck socially… no university degree or chance of getting one, cannot drive and I'm [in despair]"*. That raw testimony hit me hard because I saw myself in it: the loss of social life, the interrupted education/career, the inability to drive (I went through a period of a couple years where I wasn't allowed to drive at all due to seizure frequency), and the creeping despair. The silver lining of hearing such accounts is not the suffering itself, but the sense of validation – it's not "just me." There is a whole community of us grappling with similar issues, and that means we can share coping strategies and push for change together.

Mentally and emotionally, this journey has been a roller coaster. I've faced **depression, grief, and identity loss** as mentioned earlier. According to research, mood disorders like major depression occur in a significant proportion of TBI survivors (estimates range from 13% to over 50% in various studies), and having epilepsy on top of that can further increase psychiatric risk. I have been on and off antidepressants in tandem with therapy. Some days I mourn for the life I "should" have had if the accident never happened. On other days, I feel immense gratitude just to be alive and functioning as well as I am – I know others have it even worse. It's a pendulum between those extremes. An important turning point for me was learning to accept help and to communicate openly about my needs. In the early years, I often tried to "tough it out" and keep up appearances that everything was okay. That facade was exhausting and ultimately isolating. More recently, I've chosen to be frank about my condition with friends and colleagues. Educating them has actually made my life easier; many were willing to accommodate once they understood the real stakes. For instance, close friends now know *why* I sometimes have to cancel last minute or leave early, and they don't take it personally. One even learned how to use emergency medication (a rescue sedative) on me in case I have a prolonged seizure, which gives me peace of mind when we hang out.

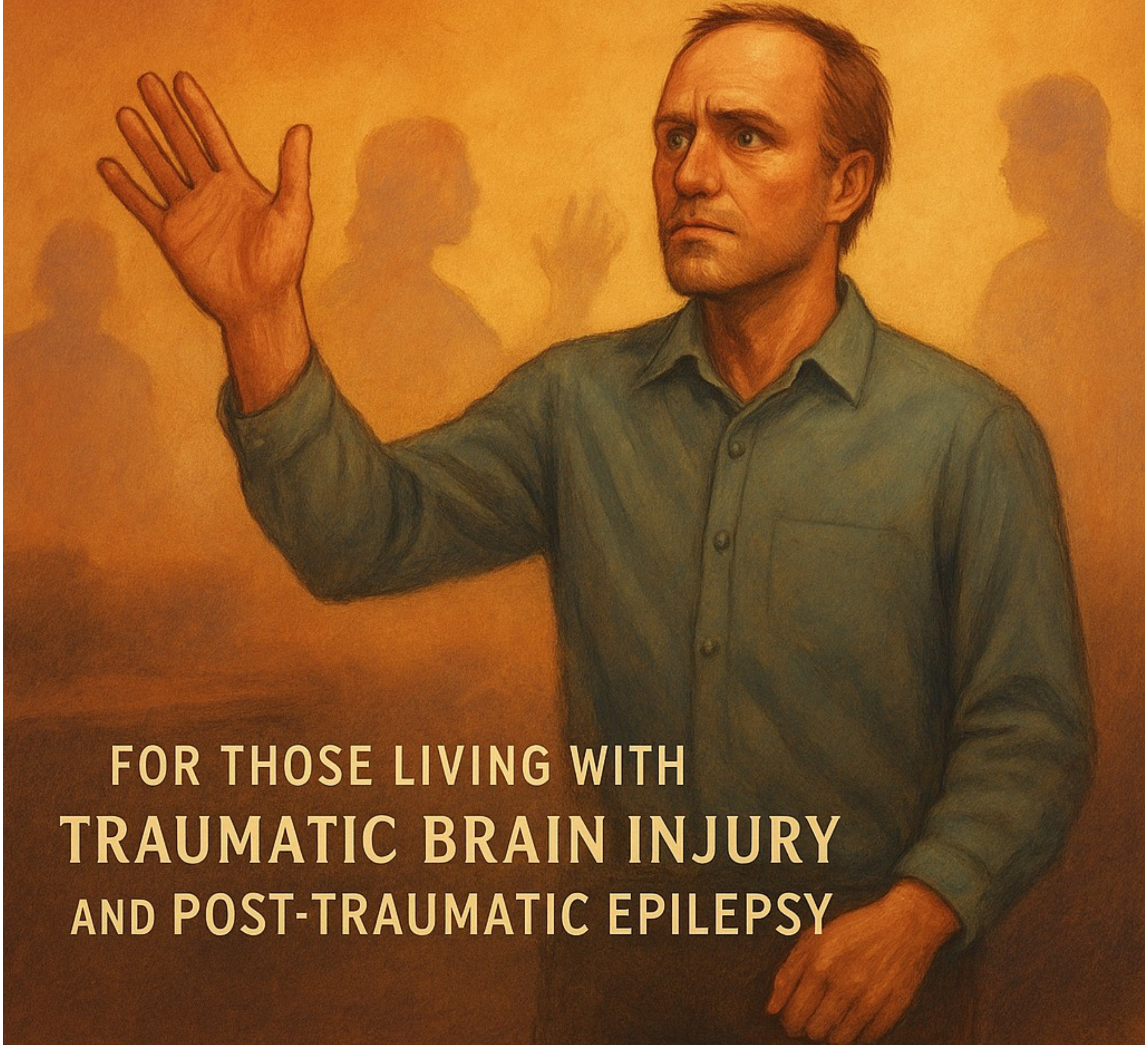
Despite all the hardship, there have been positive developments. I've discovered a passion for **advocacy and raising awareness**. I've spoken at local events for Brain Injury Awareness Month, sharing my story. I've also become involved with online communities and organizations that support epilepsy and TBI research. In doing so, I found purpose in the pain – turning my experience into something that might help others. This report you are reading is a part of that purpose. As isolating as an invisible disability can be, it also links me to a broader fellowship of survivors and advocates. We all want our voices heard.

CALL FOR CHANGE

IMPROVE CARE

ADVANCE RESEARCH

BUILD UNDERSTANDING



FOR THOSE LIVING WITH
TRAUMATIC BRAIN INJURY
AND POST-TRAUMATIC EPILEPSY

My journey highlights many areas where change is needed – in medicine, in research, and in society's understanding of neurological injuries. I want to use this section as a **call to action** on behalf of patients like me, who live in the shadows of trauma and its aftershocks.

1. Patient-Centered Neurological Care: First and foremost, healthcare providers must put patients' lived experiences at the forefront. We need a shift toward truly listening to patients. One commentary implored, "*Doctors must listen to people with brain injury.*" This might sound obvious, but as I described, too often patients are dismissed if their complaints don't line up with textbook cases or test results. I urge neurologists and other clinicians: trust that we know our bodies and brains better than anyone. If a patient with TBI says they are having cognitive issues or strange sensations, do not write it off – dig deeper, coordinate with other specialists, and acknowledge their reality. In practical terms, this could mean longer consults for TBI survivors to fully voice their concerns, routine screening for mood or memory issues in post-TBI patients, and referrals to comprehensive brain injury clinics (where available) rather than siloing care. We also need more **education for medical professionals** about post-traumatic epilepsy and the long-term sequelae of TBI. A family doctor or ER physician might see a young person with odd symptoms years after a head injury and fail to connect the dots; better awareness and training can prevent missed diagnoses. In short, **listening and empathy** are as crucial as any test when it comes to "invisible" conditions.

2. More Research on Post-Traumatic Epilepsy: It is alarming how little we still understand about why PTE occurs in some people and not others, and how to prevent it. When I had my accident, no one could tell me my odds of developing epilepsy with certainty, nor did we do anything to *proactively* mitigate that risk beyond a short course of anti-seizure meds in the ICU. We need robust research to identify biomarkers that predict whose brains are brewing epilepsy after trauma. Promisingly, there has been some recent momentum: the U.S. Department of Defense and organizations like CURE Epilepsy have launched initiatives focusing specifically on PTE. For example, a $10 million multi-year project is underway to study PTE in both military and civilian populations, aiming to develop **biomarkers and risk models for PTE and ultimately therapies to prevent it**. This is a great start, but more funding and attention are needed. Considering that TBI is a leading cause of acquired epilepsy (accounting for roughly **20% of symptomatic epilepsy cases**), preventing PTE could significantly reduce the overall burden of epilepsy in society. I call on research institutions, government agencies, and private funders to prioritize studies on **epileptogenesis after TBI** – how a blow to the head leads to hyperexcitable neural networks months/years later. We need clinical trials for interventions (whether drugs, anti-inflammatory approaches, neuromodulation, etc.) administered in the subacute phase of TBI to see if PTE can be headed off before it starts. It's too late for me in that regard, but it's not too late for the next generation of survivors.

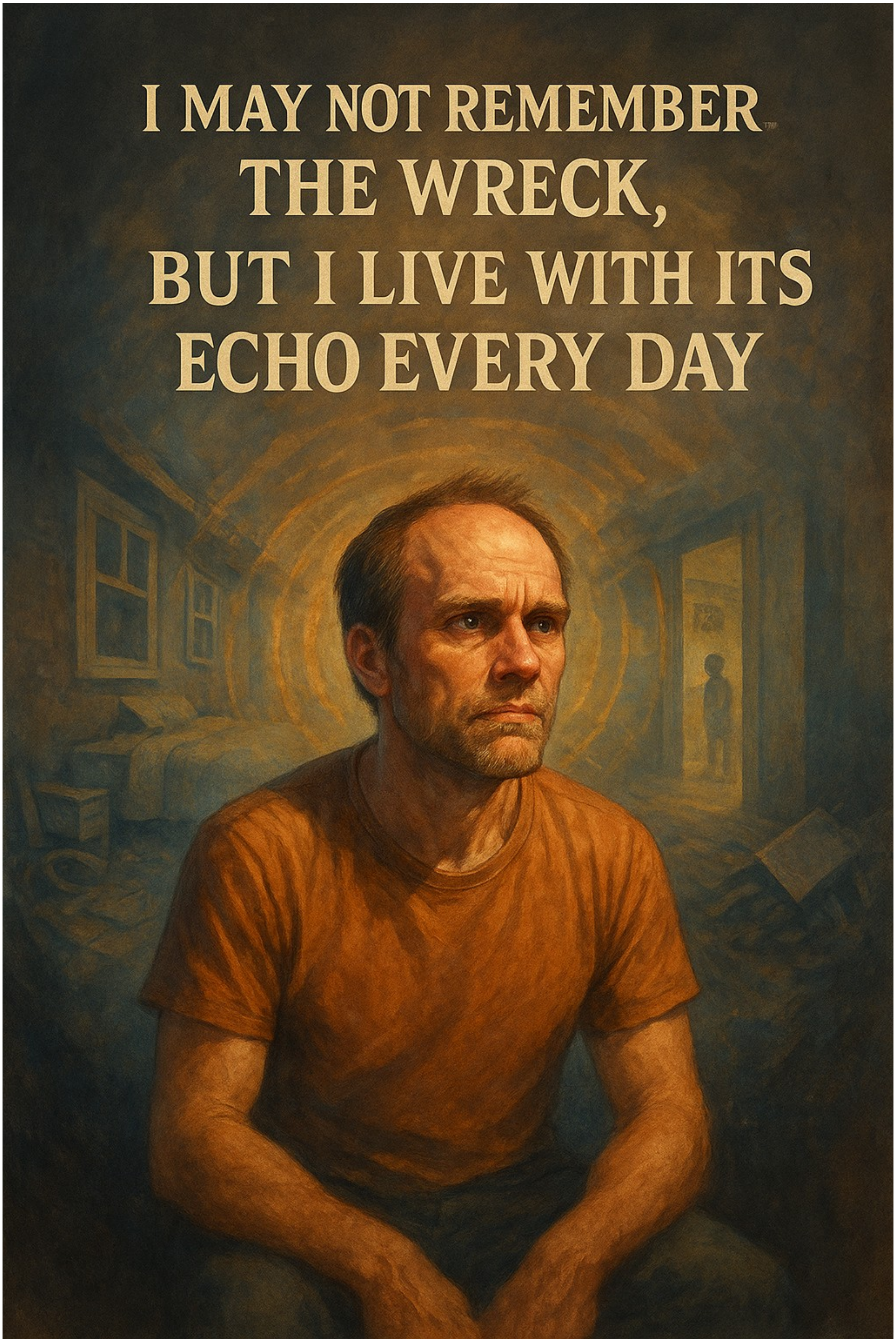
3. Better Treatment Options and Rehabilitation for PTE: Along with prevention, we must improve treatment for those who already have PTE. As I noted, many cases of post-traumatic epilepsy are refractory to standard medications. This suggests that the mechanisms of PTE might differ from other epilepsies (for instance, there's evidence that **neuroinflammation and diffuse axonal injury play a role in PTE development** in ways that might not in purely genetic epilepsies). Therefore, we should explore targeted therapies – maybe anti-inflammatory or neuroprotective drugs – in managing PTE. Moreover, rehabilitation services should be extended for PTE patients. Typically, TBI rehab focuses on the first year of recovery (physical therapy, occupational therapy, etc.). But what about when seizures kick in later and disrupt someone's life anew? It would be wonderful to have "epilepsy rehabilitation" programs that help patients re-adjust after epilepsy onset, including driving evaluations, cognitive rehab for any new deficits due to seizures, and vocational counseling if they have to change life plans. In my case, when epilepsy struck, I almost wished I could go back to the rehab hospital for a tune-up – but such a thing didn't exist. I had to piecemeal seek help (a driving safety course here, a memory workshop there). Let's create integrated rehab pathways for the unique needs of PTE patients.

4. Support and Mental Health Services: I strongly advocate for incorporating mental health into standard care for TBI and epilepsy patients. This means routine access to psychologists or counselors who understand brain injury, as well as support groups and peer mentoring. When I finally connected with a brain injury support group, it was life-changing to share experiences with peers. Organizations like the Brain Injury Association and Epilepsy Foundation do offer support resources, but many patients aren't aware of them or lack transportation to attend. Healthcare providers should proactively connect patients to these resources early on. I'd like to see every neurology clinic that treats epilepsy have information about counseling, support groups, and social services for patients – treating the whole person, not just the seizures. Another crucial aspect is caregiver support. Families of PTE survivors could benefit from education (for example, training in seizure first aid and understanding behavioral changes) and respite services. The emotional toll on caregivers can be immense, and supporting them in turn helps the patient.

5. Public Awareness and Reducing Stigma: Finally, there is a need for broader public education about TBI and post-traumatic epilepsy. We've come a long way in awareness of concussions and sports injuries recently, but the public still often conflates brain injury with either total recovery or permanent vegetative state – not recognizing the vast middle ground of "walking wounded" who live with hidden deficits. Likewise, epilepsy carries stigma and misconceptions (some still think of convulsions as rare or even as a psychological issue).

The fact is, epilepsy is relatively common – **approximately 1 in 26 people will develop epilepsy in their lifetime** – and TBI is a major contributor to those numbers. We need campaigns to highlight stories of people living with these conditions (much like how mental health issues have gained visibility through personal narratives in media). When the general public understands that a person can be intelligent, capable, and still have a disability like PTE, it fosters empathy. For instance, employers who learn about accommodating workers with epilepsy or memory impairments might be more inclined to offer flexibility rather than terminate someone. Schools could better support students with TBI histories if they know the cognitive effects. On a community level, simple awareness can save lives: if you see someone having a seizure, do you know what to do? The Epilepsy Foundation pushes an initiative called "Seizure Safe Schools" to train school personnel in seizure first aid; similar efforts could extend to workplaces and public venues. By improving public understanding, we also reduce the isolation and shame that people like me sometimes feel.

In making this call for change, I want to acknowledge that progress is happening, albeit slowly. Research is advancing – for example, newer treatments like responsive neurostimulation (RNS) and anti-seizure drug developments give hope that even drug-resistant cases like mine might achieve control. The dialogue around brain injury is improving, partly due to stories from veterans and athletes that have captured media attention. But there is much more to be done to ensure that **no one "falls through the cracks" after a traumatic brain injury**, and that those of us with post-traumatic epilepsy can live with dignity, support, and hope.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Fourteen years ago, I had a horrific accident that I **do not remember** – but I live with its echo every day. The traumatic brain injury I sustained led to a cascade of long-term complications: post-traumatic epilepsy, cognitive impairments, emotional turbulence, and social hurdles. I have shared my story and interwoven it with scientific data and other survivors' experiences to paint a picture of what life is like *after* the headlines and hospital dramas fade. For many of us, the journey is not a straight line of recovery but a winding road with unexpected setbacks, like the delayed onset of seizures.

If there is one message I hope readers take away, it is that **survival is just the beginning for TBI patients**. We need understanding, empathy, and sustained care long after the emergency lights stop flashing. I also hope fellow survivors who read this might feel a little less alone, and that some of the information here validates what they are going through. Our injuries may be invisible, but our struggles and victories are very real.

In closing, I return to that young man I was – the 26-year-old lying broken on the roadside in 2011. He couldn't imagine the path ahead, and perhaps it's better he didn't know. But I'd like to think that if he could see me now, he'd feel proud that I kept going. **Yes, I carry scars on my brain that will never fully heal. Yes, I have epilepsy and challenges that may always be part of my life.** Yet I'm still here, still *me*, and still moving forward. I share this not to seek pity or dramatize my plight, but so that others might see the person *behind* the injury and illness. If my story prompts even one doctor to pause and listen more closely to a patient, or one reader to offer compassion to someone with an invisible disability, then these words have been worthwhile. The echoes after impact continue, but with awareness, research, and support, we can help ensure those echoes ring with resilience and hope, not just pain.

Resources for Support and Further Information: If you or someone you know is dealing with TBI, post-traumatic epilepsy, or related issues, there are organizations that can help. The Epilepsy Foundation and the Brain Injury Association of America (BIAA) provide educational materials, support group directories, and helplines. Websites like BrainLine (brainline.org) offer a wealth of articles and personal stories about TBI recovery and coping. For veterans, the Department of Veterans Affairs has dedicated programs for TBI and epilepsy care. Above all, know that you are not alone and that it's okay to ask for help. The road is long, but with the right care and understanding, there is life after TBI – and even after epilepsy – that can still be meaningful and rich.