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# Life. Frayed.

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**Y**OU WORKED LATE LAST NIGHT and several early hours this morning on that book manuscript you are editing and rushing to finish so that you can finally arrive at the part of your first sabbatical you've been looking forward to for seven years. Freedom is coming. And suddenly gone. One moment you are well. The next you are not.

The Call for Papers for the Special Issue asks for theoretical framework, methodological approach, themes, significance. I don't know. My brain is tired. I haven't written academically for a long time. To weave together citations, theory, ideas: this is too hard. Still. I've published in this journal before. Twice. Both times poetry. Maybe I should try again. To write *something*. I have questions without answers. Who did this happen to? Was it me? Who/how was I before, and who/how am I now? What does it mean to have a brain injury and be a professor? One is a disability. One is an identity, a profession, a job that pays the bills. To do it, do you have to be able? No dis allowed? Can a person be a brain injured professor? How to navigate *this* space?

I try to write. These are my findings and themes.

Pain is somewhere. Maybe everywhere.

Your ears hear a sound. This long, low moan.

What is that? Until you realize it is you.

You didn't know you could make this noise, deep and low in your throat.

Try to get up.

The ice is cold against your face that hurts so much.

Someone is coming. Hands touch you. Voices ask questions. You say, I hit my head. I hit my head.

My head hurts. I can't move my arm. Your lips touch the cold ice. You ask if you are bleeding. A

little bit, someone says, just a little bit. You imagine that your face and head are cracked open and

spilling out. You are rolled over and you see the blue sky above you. It's beautiful and bright.

Strangers look down. You feel small and lost and scared. Somehow you are magically transported

to a car and your arm is tied to you with a scarf that is not yours, and two gorgeous men lean in

from each side and do up the seat belt while someone asks if you feel like throwing up and you

say yes. Later, you're told you slowly walked to the car with help and it was your mother who did

up your seat belt and then you know how wrong everything was when you dreamed the angelic

men. You don't know how you even got up off the ice. This part is a blank. Your entire bodymind is filled with panic panic panic all the way to emergency, and you are anxietieswearing nastyp prickly hotnumbpain. What just happened?

The doctor who barely has looked at you rushes back into the curtained space next to the other curtained space where someone might be having a heart attack. "Good news," she says, "Your shoulder isn't dislocated!" During her moment's breath, your self-critical mind says *see you're such a baby; you made up this pain, so you're a liar too; you could probably move your arm if you tried harder*. "Bad news," she continues, "Your shoulder is badly broken into three pieces, and here's the name of a surgeon who wants to see you next week." "What about my head?" you ask, like you've already asked three nurses. "You're fine," she says, "I've been talking to you, and I can tell you're fine. Good luck." She goes to the heart attack person.

You do not wonder why mosquitoes whine their annoying high pitch around your head, close to your ears. Taking their sudden Decempered existence for granted, you lament that you can't swat. Fractured bones mean stillness is best. Eyes closed. Sleeping sitting up in a chair. You don't mention the first-night mosquitoes to anyone. Days later you realize your ears are ringing. Loudly. Oh fuck. Confused by your blurry vision, you make an appointment to get it checked.

A colleague convinces you to still participate in a doctoral student's exam. Otherwise it will be cancelled. Guilty, you say yes. The phone by distance will work. Grad studies approved. You try to read the proposal to prepare. You've done this so many times before. But now you can't read. You blink with confusion. What you can read, you don't understand. No questions come to mind. You tell yourself you will think of questions after the presentation and during the exam. No one will notice you aren't prepared. It's just a candidacy. You go to sleep in the chair until the phone rings. You are awake for the exam, but you don't understand the presentation. You don't understand the questions. As soon as one's been asked, you forget what the conversation is about. You make up some questions. Your voice sounds like a croak. You feel embarrassed, but you can't bring strength to it. After the bathroom break, you are surprised by the phone that is turned on laying beside the chair. You hear voices calling you. Your colleagues, wondering where you are. You forgot about the exam. Your cheeks are wet with tears. No one notices. You fall asleep afterwards for a long while.

I am reduced.

A number.

Deficient.

Deficit.

I speak slowly

St-st-st-st-uttering.

I move slowly.

The world tilts dizzy.

Slow slow slow. Breathing. I'm just a shoulder, I say, I don't have a body. Just a shoulder and a hurting head. I sleep sitting up in a chair. For several bone knitting months. I sleep and sleep and sleep.

I am reduced.

A number.

Deficient.

Deficit.

Many months pass. And many more.

The number of forms to fill in with rating scales for this and that. That and this. I need help with the most basic. I'm not sure what the questions are asking. I can't follow along a line. Can't copy a phone number. Can't follow spoken instructions if they have more than half a step.

The clinic therapists want me to make SMART goals.

Disliking, dismissing my suggestions, they make goals for me. Then everyone forgets about them until my discharge date when they can click off that they've been met.

I have my own goals. Like living a life. Like learning how to grieve.

Like learning how to let go.

Saying goodbye to projects underway. Goodbye to ideas. Dreams. Possibilities.

So much is unknown now. What will become of all this formerly futued hope?

What is to become of me. Am I to be discharged from this life?

Meetings are loud and bright. Everyone is shouting at once and speaking fast. Where has civility gone? You can't follow the conversation. Your ears start ringing loudly. You go home and lay down. This was your day. Your head hurts.

Reading has been your life, your joy. Now, you read, finally. You forget what you read. The next day, no idea. It's all new to you again. You take notes. Draw character maps. Review them before you read again. You read for 10 minutes and then, so exhausted, fall asleep for an hour. You attend a presentation. It's been seven months. You have your notebook ready. The speaker is brilliant. You're excited. You try to take notes. You can't do it. A creeping fear comes over you. It's not the first time you discovered your inability to do something, but this is the most terrifying heartbreak so far. You tell them at the clinic. You mention your memory issues, again. You are sent for more tests. The results are discussed in a room of six various therapists whose mandate is to discharge you as soon as possible. As if you are an object that can be measured. And fixed. You remember this from being a teacher. The goal in these meetings was always to find the fastest solution to fixing deficit children. You always rejected this and fought for a more holistic vision. And now, here you are, where those children and parents sat waiting to be diagnosed as deficit, just drains on the system, needing to be fixed. This does not feel good. The test took over twice as long as it should have. You are slow. Your cognition is intact, but other deficits are crippling. You start to learn strategies, not to overcome them, but to live with them. They might get better. They might not. No one knows, really. You aren't very good at the strategies. You keep trying. It takes a lot of energy. You had planned to go back to work. "No," they say. "Not just now, no. Not yet." They say your expectations and the reality of your situation are mismatched.

Near the beginning, you tell the neurologist. About the stuttering. She says, "Only when you say 3 and 4 syllable words?" and laughs. "It's fine," she says, "it will get better. No alcohol. No caffeine. Be patient. It takes time." What is time? You finally return to work after a year and a half. After practicing returning to work. Writing course outlines feels like one of the greatest challenges you've ever faced. You work hard all day. The next day you can't remember what you've done. You repeat it again and then, the next day, realize you've done the same thing twice,

differently. Which should you choose? You teach a full course load. You have experience. You realize can fake it, mostly. You enjoy the students. They like the courses. You enjoy the learning culture. A phenomenal teaching assistant supports you. You bow with gratitude. This is a workplace accommodation. Having them makes you feel vulnerable and weak. You stumble with fatigue. Sometimes you're still at work long after dark because you're too tired to organize yourself to leave your office. No energy to put on your coat and walk home. After 22 months. You can't find words. Where did they go? Words for names, concepts. Authors you have loved. You know them *almost*, but the words elude you. When fatigued, you stumble when you speak. You try to hide it. You stumble with spelling. The letters are jumbled. On the board in front of students. Homonyms are crooked. You are stumped and confused in the middle of a word. You say the wrong words, not what you meant at all. Sometimes it is a similar word, and sometimes completely unlike and you are even confusing yourself. You try to make your challenges more invisible. You tell yourself you are fine and brave and strong. Try hard, very hard. The alternative is bankrupt.

You feel like your creativity is gone. You used to love thinking. You'd remember your thoughts. Play with them in your mind. Connect ideas. This is how a paper would get written. Now they sometimes come, and you love them like always, and then they drift away. Your head aches all the time. Your brain is so tired, just so very tired. You are too tired to cook, too tired to eat, too tired to move. Too tired to think. Too tired to publish. Will you perish?

After two and a half years, ongoing symptoms provoke a neuro-optometry referral. Exam results confirm experiences. You are not crazy or lazy. But you are surprised at how slow your reading tests. It explains why you work so hard yet never accomplish quite enough before paralyzing fatigue brain fog headache. Targeted exercises are prescribed. They make you dizzy. The research says they might work. As a researcher, you know "might" is not a strong promise, but you choose the side of hope and get dizzy every day while a metronome counts beats. In her report, the doctor writes big words: "Oculomotor and Binocular Dysfunction with Convergence Insufficiency," and "Over 50% of the brain's pathways play a role in visual processing, therefore it is not surprising that patients with traumatic brain injuries experience a multitude of visual difficulties... light sensitivity... migraines... unsteady ambient vision post-traumatic brain injury symptoms... hypersensitive and fragile visual system... overwhelmed by normal lighting conditions... great difficulty using screens without significant discomfort." You remember when you couldn't read at all, for six months, two years ago. Take a deep breath. Step by step. Word by word. Beat by beat.

No one wants to hear about traumatic brain injury. You were warned about this at The Clinic before returning to work. They said don't talk about it. Especially in your workplace. "There is discrimination," they say. "We've seen it. You are entitled to protections and accommodations under The Law. Just tell people you are fine. You are still recovering, say that." This is true, but you insist it's a teachable moment and you are a teacher. That you should educate people about TBIs. Maybe it's a gift and not a dis/ability. They encourage you to stay silent. They role play possible responses with you.

You tell people about the TBI, sometimes, a little bit. Some are generous. Some are not. You wonder when the patience will wear thin and then wear out. After all, productivity is god and everyone will bow to it. Even after the bough breaks, we won't even notice that we have fallen.

Until we feel the cold ice on our face and realize we can't get up. Maybe then we will finally realize there is something very wrong with this place. It takes immense courage to accept that you are now forced to live a slower, more careful life. You don't know how yet. You don't know what it means. Who/how are you? You are so able, you can do so much, you can contribute so much. But will it measure up?

I am reduced.

Fractured.

A frayed/afraid life.

I become a smiley emoji.

Often it is genuine.

You look fine, people say.

Ok then.

I look fine.

### Postscript

During recent months, I have been considering the ways this experience continues to teach me to live and think differently across all domains of my work in Teacher Education and Curriculum Studies and also about the contemporary academy. I noticed that, when teaching again last year, I became ultrasensitive to students' mental, spiritual, and physical well-being. I did everything more slowly and more simply, because I required it, but also because deep in my healing brain and bones I understood that they needed it too. And that the diverse children they would soon teach need and deserve this. Reflecting back (and also forward), there is no sense that we needed to rush faster or cover more "content." Through my teaching actions, I understand that I can recommit myself again and again to fostering forms of radical love, kindness, and inclusion, and to thinking together with teachers how this might be our first thought for our work against which all other pedagogical and curriculum decisions are held accountable.

Throughout my past 27 years of teaching, I have witnessed, first in schools and then in universities, how quantitative and calculative ways of thinking can be dangerous to human well-being and communities. As I moved through the medical system, I learned about the ways this is true also in medicine. Measured and checklisted, to ever increasingly fragmented levels, with goals made for me by well-meaning people with great confidence in their system, there was little opportunity to holistically describe or make sense of my experience. It often felt that accountability was to a test or checklist, not to actual needs of a real person, which could never be accounted for by any list or so-called "achievable" SMART goals. What remained of my dignity and autonomy were greatly diminished through this process. The many parallels with education were painful to experience. Thus, philosophy and theorizing continue to matter. Schools, like universities, are also increasingly beset with punishing performance standards for both teachers and children. There have been decades of writing, thinking, critiquing, and warning about this in Curriculum Studies (perhaps even over a century!), and still it gets worse as existence itself bows under the crushing pressures of globalized, neoliberal capitalism and the tremendous inequalities it both creates and relies upon for its life-destroying energies. Such systems foster cruelty, meanness, and disregard for anyone or anything that doesn't "measure up" to pre-determined criteria of belonging. There is little room or patience for weakness, illness, frailty or fragility, difference or diversity. Such

ways of thinking not only cause indescribable pain and suffering, but also immeasurable loneliness and life-long exclusions, particularly for those whose living and being are seen as irrelevant to the system's continuing.

I recommit myself, also, to working with new and practicing teachers to make sense together of the historical and contemporary conditions of our work *in community*. There is existential meaning in that and new kinds of possibilities for justice and peace. This includes and extends to our non-human kin. Schools emerged from the same cultural processes as industrialization, patriarchy, capitalism, and colonialism and often remain deeply entrenched in these his/stories, even while we often imagine that they do “good.” If even one person is excluded, or if these places foster or contribute to further exclusions, then they are not good enough. I continue to hope that we can do better, that I can do better. This necessitates speaking the truth (to power). To do so always risks exposure and vulnerability, yet to not do so risks accelerating the cataclysm of suffering witnessed globally: cruelty and hatred towards diversity and difference, incalculable and growing numbers of migrants and refugees (and borders and walls that exclude them), mass extinctions and changing climate, amongst so many examples. Ecologically speaking, the strongest and most resilient environments are those that are the most diverse. This has direct implications for ways of thinking about schools and universities as communities and workplaces with their powerful bent towards homogenization and standardization. Imagining instead that the highest orienting purpose of this work is to serve and support diverse life perhaps opens space and time more generously and widely welcoming for *each* unique person to completely belong, so that as David G. Smith (1999) wrote, “life itself has a chance” (p. 27). I understand my own experience and vulnerability as a teachable moment, for myself most of all. There is much (good) work to do.

### Reference

Smith, D. (1999). *Pedagon: Interdisciplinary essays in the human sciences, pedagogy, and culture*. New York, NY: Peter Lang Publishing.

