

Pain 21

Tereza Crvenković

To whom it may concern,

There is [sic] significant disability related to previous disseminated herpes zoster encephalitis with associated major stroke and residual right upper thoracic postherpetic neuralgia ... Her infection resulted from extreme immunosuppression in an attempt to salvage a failing renal transplant ... Because of the initial generalised zoster infection during her extreme immunosuppression, her post-herpetic neuralgic pain has been amplified.

— Dr R., neurologist

“This is about average for an immunosuppressed person.” Dr F., my greying, blue-eyed, nephrologist surveys the peeling, hanging, weeping flesh on my shoulder and arm, facial expression cold, bland, fixed.

Under his orders, I remain at home for 10 days, watch the virus eat away at my body, fester, blister, ooze. See the external world pass through my bedroom in splintered shards: sun-stapled carpet; spliced wall shadows; darkness speckled white.

I tremble, whimper from the pain, swing between helplessness and terror, succumb to sleep only when exhaustion decides “enough.”

Now in the ER, angry, crimson fire flares up through the thick opioid haze in my head, burns in my belly.

What, this? Average? Why do ER nurses and doctors come in to gawp at “the worst” herpes zoster outbreak they’ve ever seen?

With his one comment, my specialist shunts the extremity of this outbreak including my pain, my suffering, my fear, into the bottomless, faceless, nameless abyss of the immunosuppressed.

Dr F. tacitly reinforces that this savage outbreak, which would otherwise be an exception, is the norm, is part of the expectation for immunosuppressed people and organ transplant recipients like me to endure.

But how can human experience, human suffering, be categorised as above average for some and about average for others? Isn’t our human need for compassion, care and empathy in horrific circumstances the same across the board?

Dr F. rattles off a treatment plan. I listen to his well-practiced medical parlance, realise that the hard, callous mask is part of his polished physician’s persona, worn when faced with his own medical misjudgements.

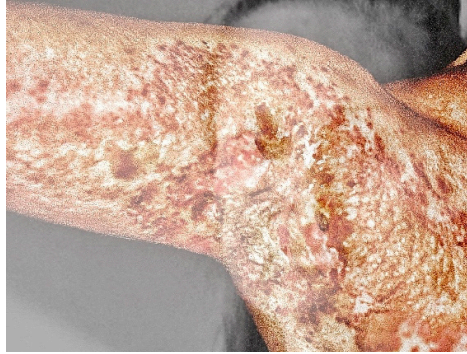
His words shrink; his coldness pushes me into free fall and my humanity tumbles through the cracks.

In the end, Dr F. prescribes a hefty, round-the-clock opioid cocktail, but no antivirals.

“Antivirals could damage your kidney further. Besides it’s too late to start.”

A few months later, I almost lose my life because of this.

About Average



“What’s she doing here? She’ll put everybody at risk.” My move from the ER to a ward where the majority of patients are immunosuppressed has been ill-considered. The shingles virus is highly contagious and potentially life-threatening to the most vulnerable. The ward manager and staff debate my condition, within earshot.

I look over at their frown-frozen brows, the fixed, gunfire-glare of their eyes. Fear punctuates the air with little black dots. She, she, she. I’m an outcast, yet have no control over the virus or its possession of my body.

On my way to a chest x-ray, a porter, with long white hair and a beard like Santa’s, yells at me when I tell him that the shingles virus has caused my pneumonia. His fear is palpable: his face blazes red as he pushes me into a dim corner of the corridor and walks away.

Two months after my herpes zoster outbreak I have a major brain haemorrhage, a direct result of the infection left to simmer in my spinal fluid.

I'm unable to sit, stand or walk; my left side is paralysed, my body withered. The injury to the nerves in my right shoulder, arm, and hand from the herpes zoster virus is severe.

And then the pain: unbearable, soul-destroying; without beginning, without end.

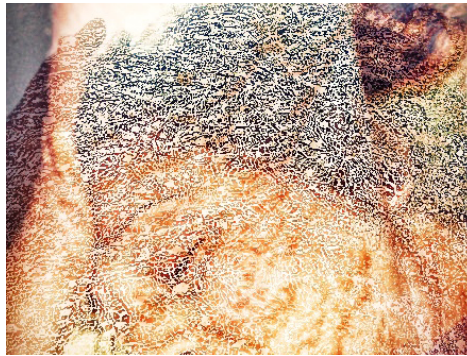
I plead for death for the first time in my life.

Wooden walking pattern, clumsy gait, stooped posture, balance unhinged.

After eight weeks in rehab, I return home, scarred, forever changed. Deficiencies from the stroke and the extreme nerve pain collide. My right shoulder—in a bid to alleviate the burden of the pain—sits hitched up towards my ear.

Pain slices through every moment, swamps my senses, drags me into its deepest, most secret recesses. My life is now a revolving door of excruciating sensations.

The Scream



At times, I feel as though I've been stabbed; subjected to electric shock; had acid thrown on

my right shoulder, across my chest, along the underside of my arm and armpit. My skin feels burnt, scalded, singed, roasted, baked, charred.

At times, it feels raw, scabbed over, dry, ready to crack; it throbs, vibrates, bubbles, crawls, grips, prickles, pinches, itches. Throughout the day and night, pressure radiates from my shoulder, builds, then explodes into intense spasms for minutes at a time. During these agonising moments, my right arm and hand—even the right side of my lip—tremble and twitch.

21 shades of pain and counting.

The pain breathes its own life, beats its own rhythm. I whimper, I cry. Sometimes, all I can do is scream.

The spasms from my damaged nerves are so bad, so terrifying, so all-consuming, I feel as if I'm going to die. My flesh, my blood, my humanity are unable to contain the burden of my distress and remain silent: shrill shrieks fly from my mouth, out from my bedroom window toward the rows of houses and apartment blocks on the neighbouring hills, out into the amphitheatre of surrounding "spectators."

During one of these episodes, I experience a sharp reminder that my voice transgresses the expectation, the requirement, reinforced so clearly by my nephrologist, of silence, to swallow my suffering: a voice in the neighbourhood shrieks right back at me.

In that moment, I acknowledge that my shrieks are disturbing, annoying, boring. But I'm beyond caring about what people might think. My shrieks contain an innate sense of loss, a recognition that

my existence as a pain-free body is gone. The pain has thrust me into a roiling, dark void of desperation unknown to the uninitiated.

If the able-bodied voice belonging to the human being behind the taunt felt this vile pain extinguish their life as they know it, they wouldn't be able to contain their suffering either.

Yet there's something else in the shrieking, primal vocalization of my pain.

Sometimes I imagine these buildings as much more than homes with people in them. In my mind, the buildings form a solid, fortress-like boundary around me.

During my worst moments, when I feel the reach of death in my pain, the fortress provides a force field, a sense of protection, safety, solace; offers to absorb and contain the extremities of my pain.

It can't get worse, won't get worse, I reason, because the fortress denies expansion of the pain into the eternity of the skies beyond.

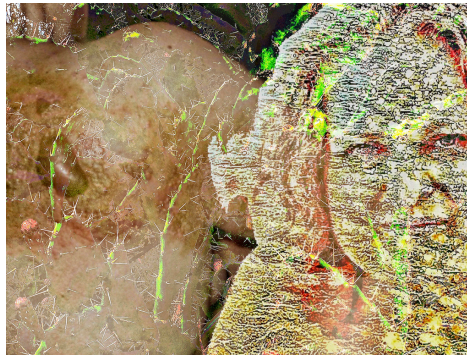
The nerve damage has affected my fine motor skills: my left, stroke-affected hand is weak; my right, dominant hand is weak and numb. I have to re-learn how to brush my hair, use chopsticks, hold a pen. My handwriting is an illegible mess of scratches.

As my pain and life progress in tandem, there are specific rules and regulations for me to follow. In order to re-enter the outer, able-bodied social world, my crying, wounded, shrieking body has to appear pain-free. In spite of everything, my existence has to appear seamless, "normal."

The stroke-pain narrative is etched on my body, yet there's a tacit understanding that pain-talk is off-limits. The bland, "I have severe chronic pain," is permissible. Anything more is unpalatable, might attract a "whinger" label, which would minimise the seriousness of my daily battles.

So, I adopt a pain-free mask, pretend my body isn't hurt, that I'm just like other people. Behind every word, every smile, every laugh, though, there is the piercing, internal scream of my pain.

Let's Pretend



Several months after my discharge from rehab, my sister organizes coffee with an old friend. I look forward to seeing her: a desire to share my big, life-changing story burns inside. When we sit down, she barely looks at me, turns her dark, glossy head of hair towards my sister, talks of her new job, new boots, travel plans.

Being invisible is excruciating. When I get home, I collapse on the small sofa in the kitchen and sob for hours.

In the end, my desire to humanise the brutality of the pain, talk about my grief and loss from the stroke, express my gratitude in being able to walk again, to breathe, to be alive, burns out.

In order to get back to my bigger life, I swallow my big story and listen to stories about the lives of others.

“You’re such a brave girl;” “You’re so strong.”

I am not.

And yet I am.

I’ve been fed the stoic acceptance narrative since the age of five, when I was first diagnosed with chronic kidney failure. No matter how painful or intrusive the procedure, I learned how to wear a mask, fool others, make my bravery believable. Perhaps this is why I readily assume the pain-free mask in public.

Underneath the smooth, masked surface, my inner landscape has supported floods of sadness, despair, rage, wild fear, emptiness. Yet in amongst all of this: courage.

Now I ache for the physically strong, pain-free transplant woman I was before all of this happened. I’m angry and afraid and grieve her passing.

“You’ll never get back to where you were.”

Behind his rigid desk, Dr F. attempts to hammer the stoic acceptance narrative into place.

Again.

His comment deepens my anger and mistrust.

I know more about myself than you ever will.

I'm not a statistic, a line, a squiggle. I'm a human being with every right to believe in my recovery. I may not get back to where I was, but the core of my humanity will never bend to expected long-term outcomes or succumb to hopelessness.

From the smoke and ash, I vow to harness the indestructible inner strength that will always be mine, commit to work with my pain and my disability.

For the first time ever, I consciously choose the acceptance narrative, not as a mask, but as an ally.

I acquaint myself with the abilities within my disability, discover how to live with my altered body. I learn to use public transport, then drive; attend yoga classes again; paint; write; cook; complete a postgraduate degree. After my first kidney transplant fails, I manage to cannulate my left arm and place myself on home dialysis, until I undergo a second kidney transplant.

Although the stroke and pain have both affected my balance and mobility, I can now walk.

How did I manage to do all of this? How do I continue? I'll never know.

I won't pretend. Living in a body fettered to severe pain is hell.

All I know is that with each day, I try to follow the light that lives inside me towards a fuller life—in whatever form possible. Hope is stronger than anything, even pain itself.

Sometimes I look down at the motley scars on my chest and right shoulder where the virus branded my flesh. I see a mess of irregular shapes and textures, bleached, criss-crossed lines, craters, pits.

Sometimes though, mesh-like patterns emerge, and I see a mass of faded links, chainmail, a suit of armour.

My life-death battle with the virus follows me like a shadow wherever I go. When I choose to step inside the shadow, there is a web of dark and light.

Grief and loss will always sit in a small box inside me. Moments when the box swings open, when the grief seeks me out and scoops me up into its cloak, will haunt me forever.

Yet now, with my pain-sharpened nervous system, the lifeworld is a cut diamond: facets flash, shine fuller, brighter, than ever before. I can taste solid gold sunlight, smell eternity in fragrant jasmine, feel cold water in the splash of a baby whale.

I am a warrior. I live in pain, but I live.

Postscript

Breathe in, breathe out.

Sometimes at the end of my yoga practice, when I lie on the floor in *Savasana* (corpse pose), the pain in my shoulder slips into silent, eternal nothingness, shapeshifts into a small black star, a pin-sized pulsar, a tiny thorn, a soft touch, a little pinch.

I know when I lift myself from the floor the scalding, wave-like spasms will resume. But this short pause, this alternative reality, this echo of my life before my existence as a pain-body, offers solace.

Maybe my pain is really just an asterisk marking a memory. Maybe it's just a blotch surrounded by a system of botched signals in my brain.

And really, that's all it is.

All, yet everything.

About the Author

Tereza Crvenković is multidisciplinary artist whose creative practice explores her lived experience of 2 x kidney transplants (1992; 2017), a major stroke (2009), chronic pain, and disability. Email: tereza.crvenkovic@gmail.com