

## Hurt and Words: On Language and Pain in Public

BY KHAIRANI BAROKKA

While writing this piece, I had a flare up, or a relapse, of extreme pain (in fact, two relapses); words that inadequately describe what is more akin to a bomb exploding inside of you. And I thought: *My god—I would be so enraged if someone told me not to describe this pain as the searingness it is, the stabbing knives, for hours on end, days. In previous years, for months. Brutality that fragments all sense of space, time, speech and even self.*

Julietta Singh's remarkable collection of essays—or, as I read them, prose poems—*No Archive Will Restore You* (2018), is one of the clearest, most honest articulations of various pains I've ever read. I am so deeply grateful for it, as a fellow brown person working in and with archives, as a fellow pained woman for many years, as a woman who has had romances archived/imprisoned online as the one she describes in the book is. Yet, after reading page 61, I had to put the book away for a good chunk of time.

On this page, Singh is discussing *A Body, Undone*, a memoir by Christina Crosby that 'writes the bewilderment of her life with quadriplegia'. In the wake of Trump's inauguration, a student of Singh's says

Aren't we all differently abled, in the end? Shouldn't we be in radical embrace of different experiences of the body? And doesn't Crosby's memoir, in her nostalgia for her life before quadriplegia, become weirdly ableist?

Not referring to all people as 'differently abled' (a term various artist-scholars steeped in disability justice, including myself, abhor) (Berghs et al, 2019; Hadley and McDonald, 2018), apart from the

fact that certain bodyminds *aren't* “differently abled” according to colonial, capitalist classification), and not wanting certain forms of disability, as Crosby’s memoir details, is somehow ‘weirdly ableist’. Singh writes, as pain sears through her:

I looked at my beloved student and thought through my body: ‘Can we put aside our training in political correctness and let pain, that inarticulate beast, sound its impossible noise? Can we listen together differently?’

My taking a step back was not because of why Singh felt what she felt, but because ‘political correctness’ triggered in me revulsion, as a term often used by the right against disability justice practitioners. Make no mistake, I would have been infuriated were I in the same position, teaching while a student presumed that to say one hates indescribable pain is ableist, as my own wall of internal fire flared and devoured me. A nightmarish scenario. However, I wanted it to be written in the book that saying pain is *always* bearable for a person, as the student cockily proclaimed, is what is ableist, rather than being ‘politically correct’. A proclamation even I, having extreme experiences of pain on the regular, need to remember to be wary of. That pain, oh so much, is multidimensional, fluid, liminal, changing from second to second within one person, each changed and changing second a whole entire tome of descriptions. That disability comprises infinite soulbody experiences.

More than four dimensions; a dimension for each cosmology a soulbody ascribes to, a dimension for each measure of time in which pain is described, a dimension allowing for the possibility of fluid change in one’s understanding of pain from minute to minute; a non-linear sense of it, a refracted, at times kaleidoscopic, in my experience, view of it. All pains are different, and subject to changing states. My description of painedness when it is level 1, as it is on a good day because I’ve been able to lie in bed longer, is not my description of painedness when I flare up the circuitry unwittingly, and my nerve damage becomes a furnace.

I don’t want to be non-disabled, though I have been subject to regular hells, at first non-stop unbearable, then from time to time. Because ‘disability’ covers those whose pain is indescribable at

times, and also those who are chronically fatigued and pained but managing their conditions—so I don't want, ever again (though it continues to happen monthly due to factors outside of my control; and even now I cross fingers and think *hopefully never again from now on*) to be pained beyond bearability, level 10 pain. I don't want *that* disability. But the disability I have two weeks out, in recovery from a relapse, in which pain is level 1-3 and fatigue is manageable? I am actually okay with this. And in *this* state, I do not want to be 'abled'. I do not want my life to be thought of as unbearable, as full of love and living as it is.

Disability is never one thing, nor is it always one thing for every person, every minute of their lives. Both pain studies scholar Alyson Patsavas and I, for instance, have written of the nauseating horrors of level 10 pain for prolonged periods of time, causing the former to want to commit suicide. But Patsavas does not want suicide as a pained person when her pain is in manageable states; she calls for a 'cripistemology of pain' (2014) that digs deeper, respects nuance and lived experience. People often think 'pained people' are one thing, and that our lives are non-stop hells. The truth is more complex, and uniform thinking about pained people lends itself dangerously to eugenics.

This fear of eugenicism—in full force during this pandemic, in which disabled women in the UK are 11 times more likely to die of COVID-19, not including additional factors of race, class, sexuality, trans experience, etc.—is what compels us to knee-jerk react to someone saying a disabled person's life is unbearable. Because that someone's subconscious thought may well be 'this disabled person should die' instead of 'this pained person needs urgent care and pain medications'.

What is ableist is to prescribe a uniform understanding of pain to everyone. Including only referring to people who have a greater likelihood of their pain being managed, to have access to doctors who believe you from the outset and meds available subsidised, and how-to's to read or programs to undergo that don't universalise one's experience of pain—these, from personal experience, can exacerbate pain in some bodies.

And certainly, Crosby's yearning for a pre-disability life can happen—it's part of the transitional process from non-disabled bodymind to disabled one. Perhaps years from now, the author in question will be past this yearning. Perhaps not. Either way, it is one life with infinite variables, including, yes, that of societal ableism, which tells us some bodies are worse than others. But we cannot inhabit others' lived realms.

The thing that is pain can be fractal explosion—so many shards knifing open so many forms of asymptotic description. Julietta Singh's pain deserves all the brilliant mirrors, sharp, she presents to us in *No Archive*. What her student said and Singh's response could be, I believe, adjacent to two hurting totems of tropes: one, that pained people are not deserving of life, a eugenicist filter on all our bruised lives—bruised so often because others do not read us as being pained, refuse to validate our often-terrors (for those of us hundreds of millions of women who've experienced indescribably horrible pain). The other, that all kinds of pain, all kinds of moments and circumstances in which pain exists, are bearable and manageable. This, too, can contribute to us playing down how bad pain can be, to the point of many of us forgoing urgent care because we've internalised the notion that it's *always* 'not that bad'.

And so: someone like Singh saying their pain is unbearable may be read by other pained people as 'and therefore all pained bodies should be wiped out'. Rather than having pain treated and believed, rather than understanding that 'I am a pained person' means such different things to each person, each moment.

It is unreal and wholly inadequate—wholly thwarting of care—that we continue to present or interpret pain as a singular experience, when in our lives, we experience infinite varieties of it. Bodily, psychically.

Pain needs to be honoured in its complexity. Saying pain is one thing, is one static point in time, is as false as saying gender feels and is expressed the same for everyone, at every moment in our

lives. It is not; it is refracted through others' cultural conditioning constantly; describing it or not affects bodies' manifestations of pain, our own bodies and others.

What is necessary is to trust our own experiences of pain, to allow for care systems that do not accuse of exaggeration nor assume all pained lives justify eugenicist notions by virtue of existing.

What is necessary is to dismantle the ableist stories that uphold sociomedical systems that kill and maim, to let us tell our stories, to stand a chance at living the kindest lives we can.

Circa 2011-2012, my first year into experiencing extreme neuropathic pain, I wrote the poem below. It was later incorporated into my one-woman show *Eve and Mary Are Having Coffee*, in which I challenge the 'invisibility' of my pain to others. Enjoy, and take care of yourselves.

### *Sliding Scale*

*What is it on a scale of one to ten.*

Is it aching, burning, raw,

Enraged and radiating,

Agonizing. Stinging.

Stabbing; is it suppurating.

Does it feel like a carcass under two tons of meat pounder,

Up and down, eternity. An apex of weight.

Is it mother's arm in the night,

The color of langsat,

Glowing radioactive as a Chevy truck

Arrives and crushes it, grates it to the asphalt,

Sparing only her rings.

Is it the mouth of a gash.

Sing it like a scream.

Who is invisible in there, is it malingering.

Is it attention you gouge out of knees

To bring them to the floor,

Joints and flesh uncertain of the stage cues.

Which act of empathy, fumbling,

All the world's pity and disinterest and love

Disguised or amplified in all the same trembling sighs.

Is it the neighbor man reaching his hand

Inside, pinning you beady-eyed

Just when you catch him in the door,

Was that a nightmare.

Is it her face. Is it his. Is it their legs

In your covers, and wondering

Which of these many weak bodies

Is weaker than yours.

Who could you get more pleasure from

In which of their open wounds.

Is it a wound.

Is it a blister, a bruise, a boil, a pimple,

An ingrown curse from an ancestor

Thick in the face and spitting through the eons,

Heckling at your flesh to carve in it.

Did it begin when you turned the corner

And the street lights came on

And a cloud looked a lot like that hobo you pass,

And everything became a cloud,

And you passed out. Was it in the bathtub.

Was it in the cubicle.

Or in the lap of a terrified stranger,

At the point of a revolver,

Because this man is not what his mama

Always thought he would be, and this is money, kid.

This is money. And I will pay you to shut

The doors of hollering grief for good

If you eat this, swallow this, believe in these studies.

This is antidote ethereal, this will stop a world

Of grief and the need to speak it.

I love you, I manufacture these compounds

In a heart grafted of selflessness and cashmere

Concern, sugar in my giving veins, just sugar, baby.



Are you telling me you haven't heard about

The mortgage like a noose and my own father's

Slit in the chest, you think it comes free.

Is it squares on a board you were born into

That began with spices in trading ships

And men in peaked headgear who terrorized

Your ancestor's chickens and worse,

So much worse you feel the sickening

Of history like a plague in all your parts,

And this came from my friend in school, miss,

Caught it from him, hysterical disease,

Are you saying colonialism didn't give you the flu

Or are you just trying to get him in detention.

Must be going around.

Must be terror so dark it spits void.

Must be a needle in the lower eyelid,

Going through the cheekbone,

Must be the heat.

We are shedding so much of our baby-faces.

We are falling apart under all of our eyes,

I mean really, disintegrating,

No wonder muscles are always breaking down.

This is a planet of slough and hell,

If you are human skin.

Now is it dermatological

Or can you feel it in the bone.

I honestly can't hear your answer, girl,

Are you dancing to show you can still

Make the party or was that a spasm

Or are you being clever.

What are these bales of letters on your tongue

When all I want to know is a number.

*Khairani Barokka is an Indonesian writer and artist in London. Her work has been presented widely, in 15 countries, and work from her Annah, Infinite series of performance installations*

*has been an Artforum Must-See. Among Okka's honours, she was a UNFPA Indonesian Young Leader Driving Social Change, an NYU Tisch Departmental Fellow, and Modern Poetry in Translation's Inaugural Poet-in-Residence. She is currently Associate Artist at the National Centre for Writing, and Researcher-in-Residence and Research Fellow at UAL's Decolonising Arts Institute. Okka's books include Indigenous Species (Tilted Axis; Vietnamese translation, AJAR Press) and Stairs and Whispers: D/deaf and Disabled Poets Write Back (as co-editor; Nine Arches), and debut collection Rope (Nine Arches).*

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Tags: ableism; archives; disability; disability justice; Julietta Singh; pain; poetry