

“We are looking for positives here”: Seeking Intersections of Pain, Grief and Disability

By Christina Crosby, PhD

Three weeks after my fiftieth birthday, I broke my fifth and sixth cervical vertebrae in a cycling accident. A branch got caught in my spokes and instantly threw me to the side, so fast I had no time to throw out my hands. My chin took the full impact, smashing my face and hyper- extending my neck. Anyone who works in rehabilitative medicine knows something of the far-reaching effects of spinal cord injury. Every person so paralyzed will live with deficits and capabilities specific to which neural networks are destroyed or compromised, so each case will pose different challenges for rehabilitative treatment. Each person must use whatever resources are at hand to understand a bodymind radically undone.

“We are looking for positives here,” Dr. Seetherama said to my lover Janet as I lay in intensive care. When I was discharged to the rehab hospital, the whole team working toward my rehabilitation was animated by this spirit (Subramani Seetherama, MD; Winnie Benjamin, RN; Danielle O’Connell, PT; and Patty D’Arena, OT). They brought to their work a life-affirming stance that encouraged me to imagine living on, even as I suffered sometimes overwhelming

neuropathic pain and deep grief for all I’d lost. Weekly meetings of the team, which included Janet and me, assured me that each knew what the others were doing, and all were concentrated on treating me. I now enjoy a manifestly abundant life. I work half time at a job I love, and I enjoy the friendship of many. My lover then still loves me now, and between us we have enough money to pay directly for all the help I need, while so many have no such advantage. Yet physical pain, though moderated by drugs, shadows every day, and fourteen years after the accident, I am not done with grieving.

I have worked for more than thirty years at Wesleyan University as a Professor of feminist, gender, and sexuality studies and English language and literature, and have deeply considered how representation informs our ideas about both bodies and mind.* As I slowly reengaged with my intellectual life, reading brought me to disability studies, and writing about my experience was a way of making sense of my new and often overwhelmingly demanding way of life.

Disability studies developed out of decades of

activism by disabled people demanding full access to the public sphere for everyone – including those seen as incapacitated and incapable of productively contributing to the greater good. Disability studies adamantly refuses such understandings of non-conforming bodies and teaches us to be wary of the so-called medical model that sees disability always as some defect that restricts the sufferer until medicine can find a cure. The social model advanced by the field declares that bodies are disabled not innately, but structurally, through doors that are too narrow, buses that don't kneel, and measures of achievement narrowly conceived. The world I encounter, for instance, disables the bodymind I am through an inaccessibly built environment that encourages me not to venture out.** Some scholars go further, and make a positive turn, arguing that so-called “disabled” bodyminds actually understand the world in new and valuable ways unavailable to so-called “normal” people.***

Defining keywords is a way to address the conceptual and political scope of any field. *Keywords for Disability Studies*, just issued by New York University Press, demonstrates the conceptual power of scholarship on disability and suggests, too, work yet to be done. This book offers short essays on words naming common concerns that have gathered significance as the field has become well-established. The entry on pain demonstrates a fierce refusal to link pain with bodies disabled not innately, but by the world around them, and rejects the view that physical or mental impairment is a necessarily painful deficit. I find this social model both intellectually persuasive and politically necessary – but nonetheless incomplete.

In *Keywords*, pain is shifted from the body to social and collective domains. We learn that in the medical model, pain is “theorized as an experience that

isolates and individualizes”.^{1(p133)} Pain is assumed to cut the sufferer off from others, because no one else can feel just what you're feeling. Too often, focusing on pain represents disability as an individual burden. To illustrate this point, we're asked to imagine a close-up of a woman in tears, sitting in a wheelchair. The default response is one of pity for her incapacities. Disability studies helps us to see that, to the contrary, “the woman's suffering is caused by an ablest environment,” as the Keywords entry on pain clearly states.^{1(p133)} I share in her pain – I have myself felt the ache of being left out, disregarded, excluded from gatherings I very much wished to join. Her tears are a mixture of grief and anger, as were mine.

It makes sense to me that disability studies actively contests the assumption that I am *confined* to my wheelchair, *afflicted* with paralysis, and my incapacities are a *sorrow* to those who love me. No wonder people working in disability studies take offense at such representations! Wheelchairs enable life – I remember the first time my physical therapist put me in a wheelchair early in my long stay at the rehab hospital. I propelled myself around the corner. My lover Janet and my friends, Ann Lou and Michael, waiting there for me all began to cry – there I was, moving again! Redefining pain as social exclusion is an accurate response to disabling attitudes and practices. Why should anyone worry about restructuring the built environment when there are so few people out in wheelchairs? This circular argument confirms the exclusion it creates and produces disability as a condition that requires not public change but an individual exemption: *you* can park here *this* time, but be sure to call ahead next time. No wonder the *Keywords* woman in the wheelchair feels the pain of being simultaneously singled out and ignored!

There is, however, much that remains to be said

about pain, and my recently published book, a memoir, contributes to the discussion.² My subtitle silently quotes Emily Dickinson, who wrote a poem to which she gave no title, which has come to be called (following established custom) “After Great Pain,” the first phrase of the first line. Here are the first two lines, followed by the last stanza.

After great pain, a formal feeling comes –

The Nerves sit ceremonious, like Tombs –

...

This is the Hour of Lead –

Remembered, if outlived,

As Freezing persons, recollect the Snow –

First – Chill – then Stupor – then the letting go –³

The poet says nothing about what has caused the great pain, but it’s clear that the one who speaks has suffered a life-changing loss. The aftermath finds her profoundly numb, drawn inevitably, it seems, into a final sleep that feels like freezing to death.

A pilot stranded for a few hours on an ice flow in the Arctic describes experiencing the physical sensation that Dickinson’s metaphor brings to her poem. “It was the first time I ever understood why freezing to death is sometimes described as . . . just like falling asleep It was like certain parts of my body just accrued this strange hush.”⁴ One time in the hospital I was mistakenly given OxyContin crushed. My gut immediately began to absorb all at once pain relief designed to be released over twelve hours. (I had a

gastrointestinal tube to feed me while my face healed, and could take very little by mouth, so my drugs – with the exception of the OxyContin – were to be crushed and sent through the G.I. tube.) Immediately, the feeling of coldness that tormented my body was eased, as was the buzzing of neuropathic pain, and my terrible grief and bewilderment simply disappeared. Below zero on the pain scale, I felt warm honey running in my veins, and I was suspended in that strange hush.

I remember that sensation of being enveloped so vividly because I was suffering terribly from a combination of damage to my central nervous system and stark, unassuageable grief for a body lost. The last four lines of “After Great Pain” create two metaphors: the speaker is stricken by grief heavy as lead and is frozen by grief as one lying motionless in the snow. How easy it would be to give oneself over to relief of “letting go,” and turn toward death. The beauty of the poem’s figurative language, which is spoken by one whose grief seems unbearable, summons body and mind together so as to reckon with what has been lost.^{****}

The pain of grief, so vividly represented here, is hard to address in the context of disability studies, where doing so is sometimes thought to play right into the devaluing of anyone anomalous in mind or body. I think otherwise.

Grief can cut through me like a knife when I see ocean kayaks on top of a car, or a cyclist with good form on the bicycle, or a Triumph motorcycle like the one I had to sell and replace with a minivan modified for accessibility. Or suddenly, out of nowhere, I will remember pleasures that I once shared with Janet, memories of a life shot through with joy. The loss of intensely embodied pleasure leaves me wounded and

bereft, and very sad. In such moments, the claim that disability is "a social and political identity" to be worn as a blazon of pride seems not to address me.

We would do better to keep such things to ourselves, some say, and have quiet, private conversations about the difficulties of our lives. I disagree. Yes, we should stress that disability is an identity created by oppression and injustice that activists and intellectuals have politicized and recast as crip pride. Yes, we should insist that living aslant normative expectations opens a space for new thoughts – the queerness of unusual minds and bodies produces new understandings about what it means to be a human being, and we should claim non-normative bodies and minds as beautiful, sexy, creative, and valuable. I couldn't agree more with these foundational arguments of disability studies. *But that's not the whole story.* I believe that keeping pain – of body and of mind – to ourselves makes it corrosive. Unacknowledged, unspoken, pain can eat away at the very commitments that enable recovery from catastrophic injury and political struggle against injustice. Representing pain and acknowledging losses that we must grieve will allow for a richer conversation, and a deeper commitment to creating the conditions necessary to sustain fully livable lives for us all.

FOOTNOTES

* Phenomenology is a philosophical tradition that has taught me much about these matters. Gail Salamon, *Assuming a Body: Transgender and the Rhetoric's of Materiality* (Columbia University Press, 2010) brings together Freudian psychoanalysis and Merleau-Ponty's studies of perception in a great introduction to these theories of subjectivity. Sarah Ahmed, *Queer*

Phenomenology: Orientation, Objects, Others (Duke University Press, 2006) brings feminist and queer theory to her discussion of the inseparability of body and mind. The philosopher Elizabeth Grosz is not a phenomenologist, but her philosophical work on embodiment immeasurably enriches the conversation; from *Volatile Bodies: Toward a Corporeal Feminism* (Indiana University Press, 1994), a critique of the body/mind dualism in European philosophy, to her recent work on evolution, she is oriented toward unthought openings (*In the Nick of Time: Politics, Evolution, and the Untimely* (Duke University Press, 2004)).

** "Bodymind" is a neologism I learned reading in phenomenology. The word succinctly states the fact that body and mind cannot be thought one without the other.

*** Disability studies includes many writers and scholars who have argued this position in one way or another. See, for example, Eli Clair, *Exile and Pride: Disability, Queerness, and Liberation* (South End Press, 1999); Robert McCruer, *Crip Theory: Cultural Signs of Queerness and Disability* (New York University Press, 2006); Tobin Siebers *Disability Theory* (University Of Michigan Press, 2008); Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity, and Sexuality* (Palgrave Macmillan, 2012); and Alison Kaifer, *Feminist, Queer, Crip* (Indiana University Press, 2013). Many other scholars are militant in elucidating how so-called disabled people are in fact creating new ways of thinking not only about their own lives, but your life, too, for all human beings live embodied lives.

Rehabilitative medicine helpfully offers a way to enrich our thinking about impaired bodies by focusing on what functions a body can perform, an

approach that qualifies and complicates the social model. See the International Classification of Functioning, Disability, and Health (ICF). <http://www.asha.org/slp/icf/>, accessed September 27, 2016.

****"Reckon" is a word that I have encountered in Maggie Nelson's books, most recently, *The Argonauts* (Graywolf Press, 2016). While "reckon" does evoke the register of ciphering, the word has a greater range than "account," which is more readily linked to the supposed certainty of numbers and keeping track of money. Judith Butler's book concerning these matters, *Giving an Account of Oneself* (Fordham University Press, 2005), has been invaluable to me in sorting through questions concerning what you can reasonably know about yourself, and what is knowable only indirectly.

References

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About the Author



Christina Crosby, Professor of English and Feminist, Gender, and Sexuality Studies at Wesleyan University, is most recently the author of A Body, Undone: Living on after Great Pain (NYU Press, March 2016), a memoir exploring what it took to create a truly livable life in the wake of a spinal cord injury that dispossessed her of her body. She is broadly interested in queer and feminist work in disability studies and studies of embodiment.