

# Narrating Disability, Trauma and Pain: The Doing and Undoing of the Self in Language

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## Abstract

This article analyses themes from Christina Crosby's disability memoir *A Body, Undone: Living On after Great Pain* through the philosophical works of Judith Butler. Both Crosby and Butler propose complementary ideas on corporeal vulnerability, the precariousness of life, relationality and interdependence. Crosby's memoir provides a critique of dominant disability discourses that affect the social formation and reception of disability narratives, such as narratives that unilaterally characterize disabled subjects as strong, resilient and autonomous while bracketing the traumatic dimension of disability out of the narrative. Crosby's book is discussed as a rich disability memoir that, while it firmly presents an account of living on, accounts for debilitating physical pain, the traumatic aspect of disability and the intense grief for lost bodily functions, abilities and life possibilities. Reflecting also on the socio-political character of disability narratives, the article considers how and why certain narratives can function critically and motivate a critical analysis of contemporary representations of disabled people. Approaching philosophically Crosby's memoir through Butler's work enables a wide-ranging consideration of topics found in the memoir such as the therapeutic nature of writing, narrative identity and its difficulties, the relations between disability studies and trauma theory, the political import of the personal and the ethico-political significance of interdependence.

**Keywords:** *Christina Crosby, disability, grief, interdependence, Judith Butler, narrative, pain, self, trauma*

## Narrating Disability as Trauma

'Trauma shatters one's most fundamental assumptions about the world, including beliefs about our ability to control what happens to us',<sup>1</sup> writes Susan Brison in her philosophically-rich autobiographical work on trauma. 'Physical pain is not only itself resistant to language but also actively destroys language, deconstructing it into the pre-language of cries and groans. To hear those cries is to witness the shattering of language',<sup>2</sup> emphasizes Elaine Scarry in her book on physical pain. 'Spinal cord injury has undone my body, bewildering me and thwarting my understanding',<sup>3</sup> Christina

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<sup>1</sup> Susan J. Brison, *Aftermath: Violence and the Remaking of a Self* (Princeton: Princeton University Press, 2002), xii.

<sup>2</sup> Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (Oxford: Oxford University Press, 1985), 172.

<sup>3</sup> Christina Crosby, *A Body, Undone: Living On after Great Pain* (New York: New York University Press, 2016), 20. Hereafter, any in-text page numbers in brackets refer to this book.

Crosby unambiguously highlights in her disability memoir. These three works – on sexual trauma, physical pain and disability brought about by spinal cord injury respectively – all highlight a common theme, namely, that such experiences are perceived as a shattering on various levels: of the body, of the psyche and of language. Moreover, they all resort to the same medium – language – to try to account for this shattering while acknowledging the inherent difficulties, both structural and personal, involved in doing so. Through accounting for these experiences, the implicit hope – although not always a celebratory hope – is that one restores a sense of self after the body has been breached, its solidity compromised, its intimacy violated and its dignity infringed. This interplay between, on the one hand, the *shattering* that trauma brings with it and, on the other hand, the use of language to *connect* the broken pieces in the aftermath of dissolution is captured in the titles of Scarry's, Brison's and Crosby's works.

This article focuses on Crosby's disability memoir, particularly her emphasis and bold portrayal of living with chronic neurological pain. Crosby's memoir will be analysed as functioning as a counter-narrative of sorts, that is, a narrative that exposes, problematizes and sometimes subverts dominant discourses and narratives of disability. This subversion is not just of dominant discourses *about* disabled people that circulate in society, but also subversion of dominant strands of thinking and speaking *by* people with disabilities themselves and *within* disability studies in general, emphasizing that discourses of disability employed by disabled individuals themselves are open to critical scrutiny as much as discourses that disempower and marginalize persons with disabilities.

By this latter point, I am referring, for example, to how discourses of vulnerability are sometimes considered as debilitating and disempowering people with disabilities by representing them as dependent, instead of independent and autonomous.<sup>4</sup> I am referring also to how rigid interpretations of the social model of disability – the model of disability that identifies the barriers enforced by social structures and organization, rather than individual impairments, as the cause of disability – have failed to account deeply for experiences of pain and loss brought about by physical impairments. Lastly, I also refer to how some disability stories tend toward the over-arching narrative structure of success, achievement, if not of a fantastical normalcy, conforming to 'the public demand for a story of healing and renewal, suffering and redemption.'<sup>5</sup> Such narrative expectations, some of which are at odds with each other, proceed at the expense of disavowing the traumatic dimension that can accompany, for example, acquired physical impairment. Crosby's *A Body, Undone* deviates from such narratives by presenting a rich disability memoir that, while firmly putting forward an account of "living on", attempts to account for the *debilitating pain*, the *traumatic aspect of disability* and the *intense grief* for lost bodily functions, abilities and life possibilities.

It must be emphasized that in no way is it being implied that there are easy and clear criteria through which to judge narratives, or that it is anyone's business to judge disability narratives as critical, subversive, or otherwise: it is not a desirable and useful

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<sup>4</sup> See Jackie Leach Scully, 'Disability and Vulnerability: On Bodies, Dependence, and Power', in *Vulnerability: New Essays in Ethics and Feminist Philosophy*, eds Catriona Mackenzie, Wendy Rogers and Susan Dodds (Oxford: Oxford University Press, 2014), 204-21.

<sup>5</sup> Christina Crosby, 'Loss is Inseparable from What Remains', Keynote at the Eleventh Annual Feminist Theory Workshop, Duke University, March 2017; available at [www.youtube.com/watch?v=8Nr-Loo6sOY](http://www.youtube.com/watch?v=8Nr-Loo6sOY) [accessed 19 June 2018]. Hereafter cited as *LIIFWR*, with page numbers in the text.

exercise and I do not feel entitled to do that. What this essay hopes to achieve, at best, is to show how Crosby's disability narrative sheds critical light on some of the intricate ways in which power functions to hinder, structure and regulate particular narrative expressions of disability.

## Writing the Self, Writing Disability

'Disability demands a story',<sup>6</sup> writes Michael Bérubé. Ample important work has been done, and continues to be done, on disability and narratives, capturing different interests in how stories about disability and self-narratives by disabled individuals are told. A significant strand of this work focuses on cultural representations of disability, for example, in films, literature and popular culture, to study how disability is portrayed and, in doing so, reveal assumptions, prejudices and societal inclinations on disability.<sup>7</sup> Another strand of scholarship on disability narratives aims to counter problematic portrayals of disability by presenting first-person accounts of what it is *really* like to live with disability and to manifest the variety of forms and experiences that disability signifies, in contrast with attempts to transform disability into a homogeneous thing that means the same thing always and everywhere.<sup>8</sup> Such work also creates spaces where disabled individuals can explore different identities than the ones that arise out of social interpellations and labelling. It also includes life writing and reflections on disability life writing that do not only present a narrative or memoir of a person with disability, but also enable critical philosophical reflections on notions such as embodiment, rationality, gender and identity and contribute to the disability movement by reflecting on socio-political aspects of disability such as rights, access and policy.<sup>9</sup> Situated in this latter strand, this article engages with Crosby's *A Body, Undone*, analysing the narrative she provides, as well as how she reflects on disability life writing itself, with a particular focus on notions of pain, grief and trauma. Such an engagement also serves to identify how Crosby's language and manner of writing are positioned in relation to, and sometimes in tension with, discourses *about* disability as well as discourses employed *by* persons with disability and, more generally, in disability studies.

The various strands of scholarship on disability and narrative cited above all highlight the centrality of language to communication and the generation of meaning.

<sup>6</sup> Michael Bérubé, *The Secret Life of Stories* (New York: New York University Press, 2016), 43; quoted in Rachel Adams, 'Disability Narratives', *Public Books*, 2016; available at [www.publicbooks.org/disability-narratives](http://www.publicbooks.org/disability-narratives) [accessed 19 June 2018].

<sup>7</sup> See Bérubé, *The Secret Life of Stories*; *Cultures of Representation Disability in World Cinema Contexts*, ed. Benjamin Fraser (New York: Wallflower Press, 2016); David T. Mitchell and Sharon L. Snyder, *Narrative Prosthesis: Disability and the Dependencies of Discourse* (Ann Arbor: The University of Michigan Press, 2000); *Framed: Interrogating Disability in the Media*, ed. Ann Pointon with Chris Davies (London: British Film Institute, 1997); *Screening Disability: Essays on Cinema and Disability*, eds Christopher R. Smith and Anthony Enns (Maryland: University Press of America, 2001).

<sup>8</sup> See Michael Bérubé, *Life as We Know It: A Father, a Family, and an Exceptional Child* (New York: Pantheon Books, 1996); John Callahan, *Don't Worry, He Won't Get Far on Foot* (New York: HarperCollins Publishers, 1989); Stephen Kuusisto, *Planet of the Blind* (London: Faber and Faber Limited, 1998); Harilyn Rousso, *Don't Call Me Inspirational: A Disabled Feminist Talks Back* (Philadelphia: Temple University Press, 2013).

<sup>9</sup> See G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: The University of Wisconsin Press, 1997); G. Thomas Couser, *Signifying Bodies: Disability in Contemporary Life Writing* (Ann Arbor: The University of Michigan Press, 2009); G. Thomas Couser, 'Introduction: Disability and Life Writing', *Journal of Literary and Cultural Disability Studies* 5.3 (2011): 229-41.

Indeed, language is the tool that bridges us with other people and what is within us with what is outside of us. ‘How can I know what you’re thinking if you don’t tell me?’, one might say in frustration at being unable to *read* someone else’s feelings. Yet, language is just *a* tool, not *the* tool we have to communicate. We all know of experiences that precede or exceed language, or experiences in which language is insufficient or breaks down because of its inability to capture “the moment”. Even in matters of research, linguistic articulations of research protagonists have been invoked against the so-called cold and hard scientific facts in such a way that narrative analysis or qualitative research are seen as more immediate gateways to people’s lives and their experiences.<sup>10</sup> However, it can be argued that even this shift from quantitative data to narratives is a privileging of sorts that assumes various things, among them that people *can* articulate essential truths about themselves through language and that these experiential truths can be linguistically captured in the first place. Narrative privileging can also come dangerously close to an ableist position of assuming that narrative capabilities are intrinsic and essential to humanity, to the extent that whoever does not satisfy these requirements of narrativity falls short of the normative category of being human.<sup>11</sup>

Moreover, narratives obtain meaning and significance through a social sphere. No matter how private the use of language might be, meaning is not privately generated. Even when it comes to ascribing meaning to private events, one must resort – one is condemned to resort – to a public medium: language. Thus, it is important to highlight that although first-person narratives are and should continue to be treated as important gateways to people’s lives, they are not the be-all and end-all of critical inquiry. A certain wariness surrounds narratives: what is being included in the narrative and what gets left behind, wittingly or not, behind the veil of narrativity? Moreover, not all narratives are treated equally; like language, they have a social existence: they are born, composed and circulate in a social sphere. And in language – in discourse – resides power.<sup>12</sup> When considering narratives in general and, for the purposes of this article, self-narratives in particular, one must be attuned to the socio-political and cultural forces – or what could be called power relations – that are necessarily operating upon them, giving meaning to narratives, facilitating their understanding and regulating their dissemination. Here, I follow Michel Foucault’s understanding of power: ‘it incites, it induces, it seduces, it makes easier or more difficult; it releases or contrives, makes more probable or less; in the extreme, it constrains or forbids absolutely.’<sup>13</sup> Adopting and adapting Foucault’s model of analysing power to the study of disability self-narratives, this article raises questions such as: What narratives of disability does power incite, induce, seduce? What narratives of disability does power make easier or more difficult to produce? Which are the more probable narratives of disability and why are certain narratives dissuaded, discouraged or kept in check? Is there a danger that resides in some narratives that makes them subject to control and neutralization by power?

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<sup>10</sup> See Colin Barnes, “‘Emancipatory Disability Research’: Project or Process?”, *JORSEN* 2.1 (2002); available at doi.org/10.1111/j.1471-3802.2002.00157.x [accessed 19 June 2018].

<sup>11</sup> See James Overboe, ‘Ableist Limits on Self-narration: The Concept of Post-personhood’, in *Unfitting Stories: Narrative Approaches to Disease, Disability, and Trauma*, eds Valerie Raoul, Angela D. Henderson and Carla Paterson (Ontario: Wilfrid Laurier University Press, 2007), 275-82.

<sup>12</sup> See Michel Foucault, ‘The Order of Discourse’, in *Untying the Text: A Post-Structuralist Reader*, ed. Robert Young (Boston, London: Routledge and Kegan Paul Ltd, 1981), 51-78.

<sup>13</sup> Michel Foucault, ‘The Subject and Power’, trans. Colin Gordon *et al.*, in *Power: Essential Works of Foucault 1954-1984*, ed. James D. Faubion, vol. 3 (London: Penguin Books, 2000), 341.

Crosby's narrative is functioning on multiple registers: on a basic level, it is a memoir detailing her life from the point of view of her acquired disability; it is also a reflection on pain, grief and trauma in relation to the experience of disability and a contribution to the politics of disability through its engagement with core notions in disability studies such as the disability movement, activism and the social model of disability. It is also a critical work of thought on disability that draws upon and incorporates insights from philosophical works on embodiment, affectivity and gender. The rest of the article elaborates on these different registers in which Crosby's work intervenes, specifically by using the work of Judith Butler, a gesture justified not only because it is rich in conceptual resources – vulnerability, dependency, relationality – that lend themselves to interpreting and further illuminating Crosby's work, but especially because in order to frame her narrative, Crosby clearly relies upon, uses and directly cites Butler's *Precarious Life* and *Giving an Account of Oneself* (see 209).<sup>14</sup>

## Reading Crosby through Butler

### Giving an Account of Oneself

Crosby's memoir opens with the facts about the impairment:

On October 1, 2003, I caught a branch in the spokes of the front wheel of my bicycle, and hurtled toward the pavement. My chin took the full force of the blow, which smashed my face and broke the fifth and sixth cervical vertebrae in my neck. The broken bone scraped my spinal cord, and in an instant I was paralyzed. There's no knowing right away exactly what impairments will result from a spinal cord injury, but as the days passed, it became clear that I had lost the use not only of my leg muscles, but also the muscles of my torso, arms, and hands, and that the loss of muscle compromised my body's circulatory systems. I also lost control of my bladder and bowels. [...] Lying in the intensive care unit of Hartford hospital, I knew very little about the present and nothing about the future. I only knew that I had been grievously injured, and was lost in space. Not until I reached the rehab hospital a month after the accident could I *begin to put into words a body that seemed beyond the reach of language*. (3; emphasis added)

What becomes immediately clear is that this accident is experienced as an undoing; not just of a body (as the memoir title suggests) but also of language, the self and the self-narrative. Yet, it is to language and narrative that Crosby resorts in an attempt to weave her life threads, think and live through her disability: 'I started writing this book to

<sup>14</sup> Judith Butler, *Precarious Life: The Powers of Mourning and Violence* (New York: Verso, 2004). Hereafter cited as *PL*, with page numbers in the text; Judith Butler, *Giving an Account of Oneself* (New York: Fordham University Press, 2005). Butler also provides an endorsement of *A Body, Undone*: 'A *Body, Undone* is a memoir about surviving in the midst of community, reflecting on loss, the interminable nature of grief and on the meaning of living on. Christina Crosby is a writer whose intellectually expansive reflection is simply awe-inspiring. With prose that can only be described as burning with lucidity and precision, she takes us through the aftermath of the accident and the gradual understanding of its implications for her physical and psychic life. An extraordinary and luminous book.' Moreover, it is presumably her who is acknowledged at the end of the book (as 'Judy Butler') in a list of '[e]arly readers of the manuscript, each of whom helped me see more clearly what the book was and what it might be, and thereby encouraged me to keep writing.' (204). Incidentally, the relationship between the two can be traced back to at least the early 1990s when Crosby contributed a chapter to a 1992 volume co-edited by Butler. See Christina Crosby, 'Dealing with Differences', in *Feminists Theorize the Political*, eds Judith Butler and Joan W. Scott (New York: Routledge, 1992), 130-43.

create something from an otherwise confounded life. Only through writing have I arrived at the life I now lead, the body I now am.' (12)

From the very beginning of her narrative, Crosby makes it clear that her narrative draws on and is inspired by Butler's work, particularly her ideas on precariousness and interdependence. In the opening pages, Crosby puts forward her guiding theme in what might be called Butlerian terminology:

I know for sure that we are much more *profoundly interdependent creatures* than we often care to think, and I know imperatively that we need a calculus that can value caring labor far differently than we do today. *Life is precarious*, a fact that has been borne in on me by my injury, recovery, and *continuing dependence on others for survival* and well-being. (4, emphasis added to show references to *PL*)<sup>15</sup>

In the opening chapter, Crosby also introduces the thematic that guides the memoir and the sentiment that will go on to conclude it, that is, the deep reach of relationality, the precariousness of life and the inarguable dimension of the dependency that sustains and supports life. This facet of life is especially foregrounded, argue Butler and Crosby, when the body is violated and/or when one suffers loss. In the aftermath of the accident that injured her, while knowing that she 'can't resolve the intractable difficulties of disabling incapacity' (189), Crosby endeavours to write about it, *to account for it*: 'How can I give an account of myself after "catastrophic injury"?' (18). Crosby echoes Butler's terminology and ideas in the following excerpt, at the end of which she provides a reference to *Giving an Account of Oneself*:

Because of my condition, I've been pondering the reality that everybody has/is a body. Your body emerges through the perception of others as different from yourself, at a touchable distance, and selfhood is not self-contained. What you want, who you are, how you feel are all brought into being over time and in relation to others, and those thoughts and feelings are repeatedly inscribed, creating powerful circuits that organize a sense of embodied self. Such is human interdependency that my self-regard depends on your regard for me. I need and want a more fully livable life, which turns importantly, if not exclusively, on this play of recognition. (18-19)

The form of self-narration, or autobiographical writing, presented in Crosby's book does not simply reflect back a stable and coherent subjectivity (an 'interiority') through writing. Rather, she captures the various performative (and dialogical) dimensions of self-narration. The self emerges through the writing itself.<sup>16</sup> Thus, Crosby's self-narration entails an eccentric and eclectic mix of confessional discourse (revealing her inner thoughts and feelings), medical truths (the facts about her injury), academic discourse (the texts she draws upon and cites) as well as hints of self-creation. The memoir does not represent a fixed truth about Crosby; rather, the truth is constituted through self-narration, whereby this is a precarious process haunted by incomprehensible realities, unaccountable facets, demands for recognition and a future-oriented concern with a self-creative *becoming otherwise*: 'Now *I need you* to know from the inside, as it were, how it feels to be so radically changed. If I can show you, *perhaps I'll be able to see*, too. The intricacies of bodymind interactions defy certainties

<sup>15</sup> At the end of these sentences is a reference to Butler's *PL*.

<sup>16</sup> On a study of how Butler's ideas on performativity could inform thinking about autobiography, see Sidonie Smith, 'Performativity, Autobiographical Practice, Resistance', *a/b: Auto/Biography Studies* 10.1 (1995): 17-33.

and confound representation, but I see no other way to go on – how else will I understand? How will you?’ (20-1; emphasis added).

This autopoietic dimension of self-narration is particularly revealing of relationality since the moment of self-creation is not a solitary or individualistic endeavour; in fact, Crosby concedes that ‘*I need you*’ in order for her to ‘*be able to see*’. The notion of an actual or implied listener is a crucial one here and reflects a recurring concern in trauma theory. Susan Brison, for example, too emphasizes this notion:

[T]he trauma survivor must find empathic listeners in order to carry on. [...] In this book I explore the performative aspect of speech in testimonies of trauma: how *saying* something about the memory *does* something to it. The communicative act of bearing witness to traumatic events not only transforms traumatic memories into narratives that can then be integrated into the survivor’s sense of self and view of the world, but it also reintegrates the survivor into a community, re-establishing bonds of trust and faith in others.<sup>17</sup>

Crosby notes that although her own relational self-narration is part of her attempt to live on, affirm her existence and relations, there are different narrative forms at play in her book. Aside from a call for recognition and self-restoration, there is also an implicit “darker” or traumatic narrative operating which Crosby repeatedly refers to as horror:

Whenever you offer an account of yourself to others, you labor to present yourself as coherent and worthy of recognition and attention, as I am doing right now. Yet because my sense of a coherent self has been so deeply affronted, *I’ve also been thinking about stories that are devoted more to affect than to reason, and because the accident and its aftermath were so horrific, horror stories suddenly make sense to me in a way they didn’t before.* Such stories gather affective intensity as their narratives develop. (19; emphasis added)

This characterization captures how the self-narrative, which essentially revolves around the corporeal damage, is shaped by intense affective states, particularly pain – both physical and psychical – and grief.

### **Grief, Vulnerability and the Body**

In her lecture entitled ‘Loss is Inseparable from What Remains’, Crosby emphasizes that her disability is a constant reminder to her of all that she has lost physically, affectively, professionally and socially: ‘[a]ll too often I’m reminded of what I’ve lost, and confronted with what I must endure to go on each day. [...] It’s true that I cried many times, every day, when I was in the hospital. I cried for all that I had lost. *A body, and a way of life* that I loved, destroyed.’ (*LIIFWR*, emphasis added)

*A body and a way of life.*

The *body* as a site of loss: Butler remarks how bodily existence is a perpetual sign and reminder of vulnerability. The body is both the site of agency but it is also that which exposes the individual to others and to potential injury: ‘[I]ives are by definition precarious: they can be expunged at will or by accident.’<sup>18</sup> The body is the site of illness, violence and debilitation. The body is also a social site – it marks the subject as ‘attached to others, at risk of losing those attachments, exposed to others, [and] at risk of

<sup>17</sup> Brison, *Aftermath*, x-xi [emphasis in original]. See also Dori Laub, ‘Bearing Witness, or the Vicissitudes of Listening’, in Shoshana Felman and Dori Laub, *Testimony: Crises of Witnessing in Literature, Psychoanalysis, and History* (New York: Routledge, 1992), 57-74.

<sup>18</sup> Judith Butler, *Frames of War: When is Life Grievable?* (New York: Verso, 2009), 25.

violence by virtue of that exposure' (*PL*, 20). Thus, although typically associated with one's private realm, the body as a social phenomenon has a public dimension: 'my body is and is not mine. Given over from the start to the world of others, it bears their imprint, is formed within the crucible of social life' (*PL*, 26). In this sociality we inhabit, 'we are, from the start and by virtue of being a bodily being, already given over, beyond ourselves, implicated in lives that are not our own' (*PL*, 28). Crosby almost literally echoes this portrayal of corporeal vulnerability and relationality when she writes about her relationship with her partner Janet: 'Our lives are intertwined, and my life is not mine alone, but shared with her' (200).

Butler argues that the grief that follows the loss of a beloved heightens one's awareness of the extent to which one is constituted through one's relations, claiming that the loss of a significant other cannot be understood as the termination of a chosen relation between two clearly distinct agents. Rather, the subject is constituted through the attachment one has to another in such a way that when one loses another, one also loses a part of oneself: 'Who "am" I, without you? When we lose some of these ties by which we are constituted, we do not know who we are or what to do. On one level, I think I have lost "you" only to discover that "I" have gone missing as well. At another level, perhaps what I have lost "in" you, that for which I have no ready vocabulary, is a relationality.' (*PL*, 22) This formulation of the experience of grief is echoed by Brison, who, in her account of the aftermath of trauma, reflects on the interplay between the feeling of losing a beloved and the feeling of losing one's sense of self due to trauma:

The loss of a trauma survivor's former self is typically described by analogy to the loss of a beloved other. And yet, in grieving for another, one often says, 'It's as though a part of myself has died.' It is not clear whether this circular comparison is a case of language failing us or, on the contrary, its revealing a deep truth about selfhood and connectedness.<sup>19</sup>

## Pain

Crosby's account continually emphasizes how, since her accident, her body became a crucible of impossible pain that makes her embodied existence unbearable at times. She also evokes past memories of when her body reminded her of possible pleasures: the body as the site of desire and their perpetually unquenchable nature. However, in the present, her desire remains unquenchable because of her 'profoundly compromised strength and tactile perception.' (119) 'Exposing sentiments that are often taboo in disability memoir',<sup>20</sup> in her account Crosby writes:

The idea of fucking still makes me happy [...]. For me, fucking is so changed from what it was that, try as I may, I cannot reconcile myself to my losses. How can I settle for a life with deadened sensation that decrees I'll never again have an orgasm? [...] How I miss the way sex used to feel! How I miss feeling my entire body – every molecule, every atom, every subatomic particle, every Higgs boson – moved by desire! (118-9)

Perhaps taboo too – at least among those who challenge to the pervasive connotation of disabled lives with lives unworthy of living – are sentiments of a death wish expressed by persons with disability, sentiments which Crosby voices: '[i]n the months after the

<sup>19</sup> Brison, *Aftermath*, 63.

<sup>20</sup> Adams.



accident, as I lay in my hospital bed unmoving and in a firestorm of neurological pain, I sometimes – many times – wished I had died at the instant my chin struck the pavement. Had it not been for Janet, my dear lover, this wish would, I believe, have gathered darkness around it to become an active desire for death.’ (7) Rather than desire and life, Crosby concedes that what move her body now are the contortions and jolts of pain, as can be seen from the evocation of such an episode of pain:

I awoke at night on fire, my skin crisping from the soles of my feet, up my legs and back, tight around my abdomen right up to just under my rib cage, and down my arms onto my hands. I was burning the way you burn when shocked with static electricity, but the shock was infinitely multiplied and running thickly, continuously under my skin. This ferocious buzzing was let loose on me by scrambled nerves that will never ever fully recover, neurological pain that could outline my body by thickly fizzing my skin, as it did that night, or more deeply penetrate my extremities, as was sometimes the case. What a horror, to finally and viscerally understand how profoundly I was hurt! (27)

For Crosby, this dimension of her disability is unsharable and uncommunicable; not only is it impossible to convey its intensity to others, but she also cannot incorporate and surmount the breakdown brought about by pain: ‘[p]hysical pain does not simply resist language but actively destroys it, bringing about an immediate reversion to a state anterior to language, to the sounds and cries a human being makes before language is learned.’<sup>21</sup>

Echoing and directly citing Scarry’s characterization of pain as fundamentally unsharable due to the way in which it breaks down language, Crosby writes: ‘[p]ain brings with it a dour companion, loneliness. I feel an unassuageable loneliness, because I will never be able to adequately describe the pain I suffer, nor can anyone accompany me into the realm of pain. [...] Crying, and screaming, and raging against pain are the sign of language undone.’ (31) Crosby discloses how her partner contests this loneliness of pain and insists that although she cannot herself actually feel the pain Crosby is feeling, she is still affected by the pain and she is pained to see her suffering while knowing that her desire to remove her pain is impossible. Nonetheless, Crosby reiterates that, ultimately, even if it is communicable, the pain she feels is a hindrance to relationality. While pain can serve as a common ground for communication – since everyone knows what pain is like – Crosby chooses not to disclose her pain whenever possible, as doing so, at best, is futile, and, at worst, damages her ties to others:

I don’t talk much about the pain to anybody other than my therapist, who is not my lover, or my friend, or a member of my family, or my colleague. To her I will complain bitterly, but not to others. I won’t complain about the pain because such complaints become corrosive, and would eat at the ties that bind me to others. It’s not that I’m bravely suffering in silence, but rather that I know there’s nothing to be done. (34)

Apart from the effects of disability on her sex life and the shattering pain, Crosby discusses how her disabled body precludes her from *a way of life* of certain social pleasures. She recounts how being a wheel-chair user marginalizes her from the heart of parties and social events, in contrast with her way of life prior to the accident. She writes:

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<sup>21</sup> Scarry, *The Body in Pain*, 4.

There I stayed. The living room was loud and crowded with people. The rooms beyond – and the food and drink – were utterly inaccessible to me. [...] Increasingly free laughter and talk came from the crowded rooms, and, sitting there, stuck just inside the front door, the party felt largely inaccessible to me, despite my ramps. I left after about an hour and went home sober and sad. (181)

Crosby's account agrees with foundational work in disability studies that maintains that it is of utmost importance to critically theorize the disablement brought about by social barriers; after all, disability studies as an academic discipline owes its roots to the disability rights movement which grew as a reaction to the unilateral equating of disability with the assumption that disability is purely a medical and welfare issue rather than being also a demand for rights and recognition.<sup>22</sup> While these historical circumstances should be acknowledged, one must also take heed of the other side of Crosby's argument in this regard, which is that alongside the emphasis on social disablement, it is as important for disability studies to think of the facets of disability, at least of acquired physical disability, as a trauma, a pain, a loss. These facets are not always in seamless complementarity with certain strands of thinking in a disability studies, as the next section shows.

### **The Politics of Narrating Disability**

Crosby's book links the themes of grief, corporeal vulnerability and relationality with broader socio-political considerations and situates her narrative in relation to tendencies of thought and discourses within disability studies. Crosby, a professor of literature, ascribes a therapeutic role to words in her attempt to restore and rebuild her self-narrative: 'I started writing this book to create something from an otherwise confounded life. Only through writing have I arrived at the life I now lead, the body I now am. I've done this work in language, because my profession is the study of literature. It's what I have and what I know.' (12) Here, a small but significant point needs to be made: given her academic background, Crosby's narrative is not just any disability narrative – it is the narrative of an educated white person with superior linguistic abilities, attuned and sensitive to the rich potentials of language and with a great mastery over words. Thus, when considering disability narratives, it is important to ask 'who is narrating?', since not everyone has access to the same narrative capabilities. Indeed, Crosby herself notes that experiences of disability differ according to the socio-political and class status of the individual and that in this regard she was quite privileged:

I am remarkably fortunate that I can continue to do the work I did before I was injured, though I'm able to work only half as many hours a week. [...] Nonetheless, with Janet's income added to my reduced paycheck, I still have enough money to be insulated from the indignities of an unjust world in which so many disabled people suffer because their welfare depends on poorly paid personal aides sent out from agencies, public transportation that is often unreliable, and housing that is only barely or not at all accessible. (5-6)

Moreover, when approaching disability narratives, one must be attuned to the discourses at play. Work in disability studies has shown that there are narratives of

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<sup>22</sup> See, for example, *Disability and Dependency*, ed. Len Barton (London: Falmer Press, 1989) and Michael Oliver and Colin Barnes, *The New Politics of Disablement* 2<sup>nd</sup> ed. (Hampshire: Palgrave Macmillan, 2012).

disability, or rather, *about* disability that are terribly hegemonic, for example narratives that describe disabled individuals as ‘inspirational’,<sup>23</sup> ‘angelic’ or, contrastingly, as ‘burdensome’.<sup>24</sup> Crosby describes the discourse at play in which her own story was reported in a hegemonic way in the press: her spinal cord injury was perceived as a tragedy which, however, was transformed ‘into a testament of human resilience and a triumph of the will.’ (*LIIFWR*) A fundraising event (reported in a newspaper article with the headline of ‘Massaging Away Tragedy’) was organized by Crosby’s massage therapist and her friends to help her buy a minivan she needed.

Besides the grave faults of these narrative arcs, which include the infantilization, objectification and marginalization of disabled individuals, one could also focus on narratives which might not immediately strike us as evidently hegemonic, including narratives from within disability studies itself which could possibly be functioning in a disempowering way. Crosby argues that a critical approach to pain and disability ‘should ironize any happy idea that disability leads to profound insight or higher understanding, despite the narrative arc that organizes so many stories about living with an incapacitated bodymind. That arc carries the troubled subject through painful trials to livable accommodations and lessons learned, and all too often sounds the note triumphant’; Crosby’s response to this dominant “progressivist” narrative is simple: ‘Don’t believe it.’ (116) Elements of this dominant narrative coincide with a celebrated model of disability in disability studies and activism: the social model of disability. As Crosby describes it:

Scholars have convincingly argued that *disability is not a personal attribute* of crippled bodies or minds, *but a social phenomenon* that bars the full participation in public life of persons so impaired. Impassable barriers and narrowly conceived measurements of ability make it hard to acknowledge and address nonnormative bodyminds. [...] Disability is created by building codes and education policy, subway elevators that don’t work and school buses that don’t arrive, and all the marginalization, exploitation, demeaning acts, and active exclusions that deny full access and equality to “the disabled.” (6-7; emphasis added)

Crosby approvingly cites the social model of disability, as well as the affirmative side of the social model that resulted in ‘disability-positive’ movements such as neurodiversity, crip pride and deaf culture.<sup>25</sup> According to this affirmative self-identification, rather than disabling, ‘neuro-atypical[ity] endows some with enviable abilities of memory,’ deafness is regarded ‘as a fully elaborated culture, not a disability, [and] Crip Pride turns the table on the disabling world, and orients non-normative bodyminds to a future of our own making’ (*LIIFWR*). Crosby supports all of this, both philosophically and politically.

Yet she suggests that such models foreclose something: namely, they preclude possibilities of expressions of disability that may not fit in smoothly with the main tenets of these models: ‘[t]he social model of disablement is just that, a social *model*. The emphasis on pride that contravenes pity makes discussing chronic pain difficult, and forecloses what is for me, the necessarily interminable work of mourning the loss of

<sup>23</sup> Jan Grue, ‘The Problem with Inspiration Porn: A Tentative Definition and a Provisional Critique’, *Disability and Society* 31.6 (2016): 838-49.

<sup>24</sup> S. E. Smith, ‘Disabled Children Aren’t Burdens – or Angels’, *This Ain’t Livin’*; available at [meloukhia.net/2014/09/disabled\\_children\\_arent\\_burdens\\_-\\_or\\_angels](http://meloukhia.net/2014/09/disabled_children_arent_burdens_-_or_angels) [accessed 19 June 2018].

<sup>25</sup> See John Swain and Sally French, ‘Towards an Affirmative Model of Disability’, *Disability and Society* 15.4 (2000): 569-82.

an able body' (*LIIFWR*).<sup>26</sup> Crosby is definitely not arguing that we should resort to models that treat disability solely as debilitating; rather, she is shifting our attention to what may be left out from the social and affirmative models,<sup>27</sup> pointing out that not surprisingly there is 'so little writing in disability studies [that] concentrates on pain or mourning' (*LIIFWR*). Such affective states place emphasis on what is *lost* because of disability or impairments, thus going against basic premises of the social model. For Crosby, '[t]o focus on intractable pain, then, or grief at the loss of able-bodiedness [...] may be thought to play into a pathologizing narrative that would return disability to "misshapen" bodies and "abnormal" minds' (7). Her account emphasizes that while the social model has had crucial historical and socio-political efficacy, it is not – and it cannot pretend to be – an exhaustive and totalizing model of disability. It leaves a lot unaccounted for, especially matters of pain and mourning, and facets of her relationship with her partner: '[t]hat I mourn my lost body and the world of delights Janet and I elaborated together, is hardly speakable in the critical discourse of disability' (*LIIFWR*).

Crosby identifies the ways in which certain disability narratives are excluded and argues that presenting her self-narrative in the way she does is not only a personal need, but is also an attempt to resist certain tendencies within disability studies itself that may function in a normalizing way: '[d]espite their strategic elision in disability studies or transcendence in happy stories in the popular press about trauma overcome, bodily pain and grief persist, to be accounted for as best one can. This book is my contribution to that record' (7). Thus, the memoir can be seen as a response to what she perceives as spaces *within* disability studies itself and among disabled individuals themselves that serve to hinder rather than facilitate and encourage the expression of the diverse facets of disability, notably the facet of grief, loss and trauma that some disabled individuals feel the need to express. Besides their utility for individuals, such expressions may also function to widen the sphere of disability which can be narrated. Hindering this space of narrating can function to censor and preclude disabled individuals from narrating in their preferred mode aspects of their lives which they deem to be crucial, or to do so at the risk of possible rebuke. Crosby recounts one such episode of rebuke: '[w]hen I presented some of this work to a study group, one guy in a wheelchair more or less told me to "man up" and get on with my life' (7).

Notwithstanding the gender misidentification<sup>28</sup> and the various problems associated with the toxic masculinity implied in 'man up', this remark can be seen as indicative of a wider problematic in disability studies that was identified by, among

<sup>26</sup> For a similar critique of the social model of disability, see Tom Shakespeare and Nicholas Watson, 'The Social Model of Disability: An Outdated Ideology?', in *Exploring Theories and Expanding Methodologies: Where we are and where we need to go*, eds Sharon N. Barnartt and Barbara M. Altman (2015), available at [https://doi.org/10.1016/S1479-3547\(01\)80018-X](https://doi.org/10.1016/S1479-3547(01)80018-X) [accessed 19 June 2018]. Mike Oliver, a main proponent of the social model of disability, has himself characterized the social model as a 'practical tool, not a theory, an idea or a concept.' Mike Oliver, 'The Social Model in Action: If I Had a Hammer', in *Implementing the Social Model of Disability: Theory and Research*, eds Colin Barnes and Geoff Mercer (Leeds: The Disability Press, 2004), 30, quoted in Tom Shakespeare, 'The Social Model of Disability', in *The Disability Studies Reader*, ed. Lennard J. Davis, 2<sup>nd</sup> ed. (New York: Routledge, 2006), 199.

<sup>27</sup> For other models of disability, see Jan Grue, *Disability and Discourse Analysis* (Surrey: Ashgate, 2015).

<sup>28</sup> *A Body, Undone* contains various references to and analyses of gender in relation to disability, including episodes where she is misidentified: 'I'm now misrecognized as a man more often than ever before, almost every time I go out' (60). Incidentally, even Crosby's remarks on gender can be read in light of Butler's work on gender performativity.

others, Susan Wendell with the image of the ‘healthy disabled’ that is perpetuated at the expense of relegating and silencing concerns raised by individuals who suffer from chronic debilitating pain.<sup>29</sup> Criticisms of the harms resulting from the excessive medicalization of disability – criticisms that Crosby confesses ‘I now understand better’ (6) – have inadvertently circumscribed the narratable realm of disability. According to Wendell, ‘[b]ecause disability activists have worked hard to resist medicalization and promote the social model of disability, activists sometimes feel pressured to downplay the realities of fluctuating impairment or ill health.’<sup>30</sup> Thus, refusing to acknowledge and account for vulnerability ‘may perpetuate our culture’s devaluing of dependency and inflating of the value of self-sufficiency’. Disability studies must move away from masculinist theorizing by presenting a more inclusive approach to disability that ‘does not exaggerate the value of strength and independence.’<sup>31</sup> Crosby’s work is a step in this direction by continually highlighting the value of care work and the virtues of interdependency throughout her memoir, especially in a chapter specifically dedicated to her care worker, Donna, and the concerns raised by how much care work is undervalued, both emotionally and financially. Crosby narrates how she is extremely dependent on the care of her carer, a duty which her carer executes with love. However, Crosby importantly views this work from a political lens and connects it with broader social inequalities with which it is uneasily entangled. On the one hand, Crosby rightly highlights how an ethic of care fosters an intimate relationality: ‘I love her [Donna], and she loves me, for a decade of intimate care has created an intimate bond’ (37). On the other hand, Crosby also points out that this intimate bond has brought her in proximity to the struggles that care workers face with debts, bad housing, long working hours knowing that being unwell or having a bad day at work may mean not being able to have enough money to last the month, the tiresome work of exertion involved in handling people requiring assistance to move, to stand and to satisfy their basic needs: ‘I know in a way that I never could have learned otherwise than through such an intimate relationship how bitterly, sometimes desperately, hard it is to be working poor’ (37). Care work entails ironic inequalities in that, aside from working under continually stressful and terrible work conditions, the carers can end up injured themselves and not be able to tend to their needs, or depend on someone to care for them. These realities

<sup>29</sup> See Susan Wendell, ‘Unhealthy Disabled: Treating Chronic Illnesses as Disabilities’, *Hypatia* 16.4 (2001): 17-33; Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996).

<sup>30</sup> Wendell, ‘Unhealthy Disabled’, 22. Here she also cites Cheryl Marie Wade who criticizes the reluctance among disability activists to acknowledge weakness and vulnerability (‘Identity’, *The Disability Rag and Resource* (September-October 1994): 32-6.

<sup>31</sup> Anita Silvers, ‘Feminist Perspectives on Disability’, *Stanford Encyclopedia of Philosophy*, 2013; plato.stanford.edu/entries/feminism-disability [accessed 20 June 2018]. See *Disability and Dependency*, ed. Len Barton (London: Falmer Press, 1989) as an example of work focusing on how policies and practices create the disabled individual as a subject of dependency and how this goes counter to the ideals of empowerment and independence espoused (for good reason and in specific socio-historical contexts) by the disability movement. A critique of a unilaterally negative portrayal of dependency in disability studies is presented by Eva Feder Kittay, ‘Dependency’, in *Keywords for Disability Studies*, eds Rachel Adams, Benjamin Reiss and David Serlin (New York: New York University Press, 2015), 54-8 and *Love’s Labor: Essays on Women, Equality, and Dependency* (New York: Routledge, 1999). The apparent tension between the emphasis of independence as a core value in the disability rights movement on the one hand and the critique (which has also come from within disability studies itself and not just from without) of an exaggerated emphasis on independence of autonomy on the other hand has been studied, with a focus on life writing, in Rachel Adams, ‘Disability Life Writing and the Problem of Dependency in *The Autobiography of Gaby Brimmer*’, *Journal of Medical Humanities* 38.1 (2017): 39-50.

highlight that the work of care is, ultimately, *work* and should be treated as labor. Thus, while recognizing that ‘money cannot begin to measure the value of her [Donna’s] work’ (43). Through her narrative, Crosby reflects on the virtues and affects of care, but importantly connects the work of care to the broader socio-political realities in which it is situated. To do so, Crosby writes, is ‘to link my dependency to a broader vision of caring labor and reproductive work. *It is to see the political in the personal and the personal in the political*’ (42; emphasis added).

### **Acknowledging Trauma, Living on Interdependently**

Crosby’s narrative functions as a possible counter-narrative of disability; “counter” not in the sense of going absolutely against other narratives of disability, as if these occupy a homogeneous and fixed pigeonhole. Her account serves to widen that which is understood as disability, both narratively and affectively, especially with close regard to the dimensions of grief and trauma. However, the narrative is not a unilateral tragic story of despair. After all, the memoir, which is subtitled ‘living on after great pain’, does resort to a notion of living on. It is *living on*, but it is living on *after great pain*, or rather *living with or despite* the pain. Crosby’s account tries to account – impossibly – for various shatterings: the shattering of her spinal cord, the shattering nature of pain and the shattering of language that this brings with it.

Yet it does not stop there. Although *A Body, Undone* is not a celebratory narrative, its hope lies in the moving account it gives of human interdependence, announced in the opening chapter: ‘I know for sure that we are much more profoundly interdependent creatures than we often care to think’ (4). The memoir then concludes with the same insight; in the true spirit of really recognising the power of interdependence, Crosby’s book ends with a 5-page long acknowledgements section literally showing how her life is intertwined with other lives: ‘[p]aralysis and pain have impressed on me something that I knew before breaking my neck, but understand now with vivid clarity – the simple and profound fact of human interdependence’ (203). This is not meant as a sombre concession but as a celebration of dependency: ‘I have no wish to embarrass you or mortify myself, but I do believe that living *in extremis* can clarify what is often obscure, in this case the fragility of our beautiful bodies and the dependencies of all human beings’ (10). Dependency, rather than a fact to be eschewed, is understood as a life-affirming reality. In this thought too, Crosby is echoing Butler’s recognition that exposure implied by vulnerability and dependency, at times unwanted if not potentially traumatizing, is nonetheless key to life and to living on after great pain: ‘Let’s face it. We’re undone by each other. And if we’re not, we’re missing something’ (*PL*, 23). Crosby’s book is a serious celebration of interdependence, acknowledging her dependence on her partner, her career, her friends and peers. In response to discourses that privilege autonomy and independence while presenting dependence as a negative thing to be eschewed, Crosby mobilizes a counter-discourse of dependency and care that aims to stop pitting dependence and independence against each other and instead attempts to redefine the category of the human in terms of a continuum of dependencies.

Throughout *A Body, Undone*, Crosby often describes her disability as ‘horror’. In a chapter toward the end, titled ‘The Horror! The Horror!’ (184-97), whose title echoes the end of Joseph Conrad’s *Heart of Darkness*, pain and disability are discussed in relation to realist literature, particularly Eliot’s *Middlemarch*, which Crosby asked to be read to her while in hospital. Crosby argues that in realist literature, the world is

‘comprehensible, and rationally ordered [... unlike] the neurological storm of spinal cord injury’ (187). That is why she confesses that she understands why disability memoirists wittingly or unwittingly resort to the realist narrative arc in their writing in an attempt to reclaim some form of narrative coherence in their life and self-understanding. Crosby admits that even if she herself may have resorted to such realist and stabilizing narrative conventions in her own memoir, she considers her story of profound neurological damage as more akin to a horror story, ‘a literary genre governed not by rational exposition but rather by affective intensification and bewilderment’ (189). Interestingly, Adriana Cavarero also concludes her book *Horrorism* with an appendix titled ‘The Horror! The Horror! Rereading Conrad’.<sup>32</sup> Besides their choice of titles, Cavarero and Crosby can be compared on how they both read horror in relation to vulnerability, particularly in tandem with Butler’s elaboration of the notion of corporeal vulnerability. Cavarero’s work on horror, although rooted in a discussion of contemporary violence, terrorism and mutilated bodies in particular, highlights how the truly horrific is that which strikes the human in its corporeal vulnerability, in that part of one’s self which exposes one to care and affectionate touching on one hand and, equally, to violence and harm on the other. This could be said to link disability, horror and trauma in Crosby’s book as well as theoretically.

Crosby insists that it is amid this horror, amid this possibly traumatic ‘constitutive vulnerability’,<sup>33</sup> and not by disavowing it, that she can find the capacity to live on. She admits that the grief she feels is gray – ‘[l]ife no longer feels radiant’ (12) – and that she cannot relish in mundane enjoyments any more since she is immersed in grief. Nonetheless, she wants to hold on to the grief insofar as she can vicariously experience these pleasures through her past self and through recollection: ‘I don’t want to forget how those pleasures felt in my body’ (12); ‘I may be perverse, but I’m terrified of what I’ll lose in making my peace with what I’ve lost’ (197). Crosby thus continually highlights the rich meanings that grief continues to have in her life; indeed, that she can only *live on through grief*, not as something she must overcome but as hope that guides her onward: ‘I am certain about one thing – whatever chance I have at a good life, in all senses of that phrase, depends on my openness to the undoing wrought by spinal cord injury, because there is no return to an earlier life’ (20). This ‘openness’ is not just past-oriented: ‘I am no longer what I once was – yet come to think of it, neither are you. All of us who live on are not what we were, but are becoming, always becoming’ (201-2). Thus, the grief mobilises a future-oriented commitment to living on and becoming otherwise.

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## **Nararea dizabilității, traumei și a durerii. Facerea și desfacerea sinelui prin limbaj**

### **Rezumat**

Acest articol analizează teme din jurnalul dizabilității al Christinei Crosby intitulat *A Body, Undone: Living On after Great Pain* prin operele filosofice ale lui Judith Butler. Atât Crosby cât și Butler propun idei complementare asupra vulnerabilității corporalității, precarității vieții, relaționalității și interdependenței. Jurnalul lui Crosby furnizează o critică a discursurilor dominante asupra dizabilității, ca de exemplu acele narațiuni care caracterizează în mod unilateral persoanele cu dizabilități ca fiind puternice, optimiste și autonome și care exclud din narațiune dimensiunea traumatică. Cartea lui Crosby este interpretată ca un jurnal al dizabilității

care, în timp ce prezintă o narațiune a supraviețuirii, încearcă să nareze durerea fizică debilitantă, acel aspect traumatic al dizabilității și durerea intensă provocată de pierderea funcțiilor vitale ale corpului, ale abilităților fizice și ale posibilității de a trăi o viață normală. Reflectând și asupra caracterului socio-politic al narațiunilor despre dizabilitate, articolul ia în considerație cum și de ce anumite narațiuni pot funcționa critic și motiva o analiză critică a reprezentării contemporane a persoanelor cu dizabilități. Abordarea filosofică a jurnalului lui Crosby prin opera lui Butler ne permite să analizăm în profunzime subiecte regăsite în jurnal, respectiv natura terapeutică a scriiturii, identitatea narativă și dificultățile sale, relațiile dintre studii asupra dizabilității și teoriei traumei, intruziunea politicului asupra personalului și semnificația etico-politică a interdependenței.