

Disability and the Potential of Experimental Forms

Audrey Heffers, Illinois State University

Introduction: Anti-normative Bodyminds, Anti-normative Storytelling

When I began researching disability and illness memoirs, I realised there were plenty to pick from. I have never, in my recollection, been assigned such a memoir—or even an essay—during any of my degrees in creative writing. Many of the memoirs that I had read followed traditional structures—chronological order, chapters on self-contained topics, clear and precise narration. But my interest soon turned to more experimental and hybrid possibilities. When I discovered Sonya Huber’s *Pain Woman Takes Your Keys, and Other Essays from a Nervous System*, it offered a text full of unconventional craft choices, as the essays convey the confusing, draining, and painful experience of chronic illness and disability.

Alice Hall writes in *Literature and Disability* that since many recent works of disability life writing are closely aligned with activist aims, they challenge both the status quo and the conventions of the genre of life writing itself; these accounts often shift the focus from a view of auto/biography as an individualistic endeavour to create narratives that chart the recognition of a collective identity.⁴² And Sonya Huber writes in *Voice First: A Writer’s Manifesto* that “[i]n our rush to persuade, to figure out what we’re arguing for and against, to conform to audience expectations, to fall in line with the way others express themselves in well-established genres, we lose touch with the wild inventiveness of writing. And as we lose that wildness, we may also lose our writing’s power, because inventive text often works better than cookie-cutter text.”⁴³ Hall specifically identifies “activist objectives” as the motivation for challenging the established

norms of life writing, emphasising the importance of individual self-expression in literary works.⁴⁴ This craft consideration is both textual and extratextual; it reasons by wielding an interior logic of how the text operates with a sense of a real author’s goals for how the text will be received. Huber draws attention to a rationale for innovation: “wildness” (which can certainly align with structural and narrative variations on traditional memoirs) is connected to “power.”⁴⁵ And power is a tricky thing for marginalised writers to navigate, even when telling a narrative about their own lived experiences.

The “established genres” of memoir that Huber alludes to overall prioritise linear narratives of time, grammatically traditional expressions, and the prosaic over poetic. Experimental and hybrid styles, however, allow for more freedom to explore the particularities of disabled/ill experience outside of able-bodied, able-minded, and neurotypical norms, often through techniques such as nonlinear storytelling and poetic engagement with language. Formal innovation follows personal experiences that don’t necessarily cohere in culturally expected ways.

Many disability and illness memoirs follow the paths of traditional craft, which can help with legibility for a broader audience of both abled and disabled readers. *Blind Man’s Bluff* by James Tate Hill and *Deaf Utopia* by Nyle DiMarco, for example, are organized primarily chronologically and use grammatically traditional prosaic expressions. *Sick*, a memoir by Porochista Khakpour, does not have quite the same linear fidelity; Khakpour instead organises chapters/essays by place. However, the more traditional grammar, prose, and scene building are still intact. This

⁴² Alice Hall, “Disability Life Writing,” in *Literature and Disability* (Milton Park, England: Routledge, 2016), 133.

⁴³ Sonya Huber, *Voice First: A Writer’s Manifesto* (Lincoln, Nebraska: University of Nebraska Press, 2022), 50.

⁴⁴ Hall, “Disability Life Writing,” 133.

⁴⁵ Huber, *Voice First*, 50.

contrast between “traditional” and “experimental” can also be observed in two comparable memoirs that take different approaches. In *The Collected Schizophrenias*, for instance, Esmé Weijun Wang gives deep insight into the experiences of psychosis and hallucinations through a very clear voice, building more traditional literary scenes. However, Stephanie Heit, who also writes about mental illness, describes her work *Psych Murders* instead as “a book of hybrid memoir poems about my experiences of shock treatment, memory loss, psych hospitalizations, and bipolar extreme mind states.”⁴⁶

Anti-normative, here, is an expansive, multi-faceted term. Experimental form choices, for example, can be anti-normative. However, what is anti-normative can also apply in terms of who is centralised in narrative. In a cultural landscape where centralising an abled writer is normative, centralising a disabled writer can become anti-normative; this also holds true in whether writing adheres to the normative practice of focusing on a primarily abled audience, versus writing that is anti-normative in terms of its focus on a primarily disabled audience. Sarah Fawn Montgomery writes about how “[w]riting about ourselves is difficult enough as nonfiction writers, but disabled writers face the burden of contextualizing their lived experience for an audience that does not inhabit the same world—an audience that sometimes fears, hates, and polices disability.”⁴⁷ And in *Literature and Disability*, Hall discusses Anne Finger’s assessment that “[d]isability life writing is also often informed by conventional narrative scripts such as the triumphant recovery story or narrative of overcoming.”⁴⁸ If an abled audience is centred, a disabled writer comes up against the need to be “relatable,” to follow legible and familiar cultural narratives such as the seeking of cure (which has nuanced differences from seeking diagnosis/seeking answers), inspiration porn, and/or the inherent tragedy

of disability/disabled life. Experimental narratives can be an act of unnarrating cultural narratives.

Cultural Narratives & Documentation

In working toward empathy, experimental forms can convey disabled experiences on a deeper level. In this way, form can be used to enhance thematic explorations of these specific experiences. Huber writes that she “[f]ound support from other disabled writers, and the work they’d done to reframe disability as an insight-giving window into reality, rather than a deficit.”⁴⁹ Society frames people’s narratives. Disabled/ill people are often on the margins of that frame. When disabled/ill writers have the power to frame their own narratives, the stories change. The way disability and illness are discussed changes; the humanity assigned to disabled/ill people changes. This shift allows readers to alter their own mindsets, to see the specific opportunities where disabled/ill people have to provide insight into different realities.

Gwendolyn Paradise writes, for example, about how “[m]y hearing loss allows me to experience a reality that others do not.”⁵⁰ Rather than becoming narratives of deficit, these can become narratives of possibility. I explore such possibilities in my own writing. What happens when medical forms and communications are rewritten by the disabled/ill person they speak about?⁵¹ What happens when the literal script of a doctor’s visit where the patient is disregarded is penned instead by the patient?⁵² What happens when dictionaries—lexicons that codify us—are rewritten from disabled/ill perspectives?⁵³ What opportunities can playing around with these different authoritative forms have in eliciting the empathy of the reader when they come to know what we know?

Huber plays with this technique explicitly in *Pain Woman Takes Your Keys and Other Essays from a Nervous System*. For example, in “Alternative Pain Scale,” Huber rewrites the medical pain scale that

⁴⁶ Stephanie Heit, “Disability as a Creative Practice,” *Mad in America*, published March 17, 2023, <https://www.madinamerica.com/2023/03/disability-as-a-creative-practice/>.

⁴⁷ Sarah Fawn Montgomery, “(Dis)Ableing the Creative Writing Workshop,” *Essay Daily*, published September 9, 2019, <http://www.essaydaily.org/2019/09/sarah-fawn-montgomery-disabling.html>.

⁴⁸ Hall, “Disability Life Writing,” 132.

⁴⁹ Huber, *Voice First*, 4.

⁵⁰ Gwendolyn Paradise, “Sudden and Marvelous Invention: Hearing Impairment & Fabulist (non)Fiction,” *Uncanny Magazine*, published 2019, <https://www.uncannymagazine.com/article/sudden-and-marvelous-invention-hearing-impairment-fabulist-nonfiction/>.

⁵¹ Audrey T. Carroll, “The Pain Scale,” *Glassworks Magazine*, published October 1, 2023, <https://issuu.com/glassworksmagazine/docs/issue27>.

⁵² Audrey T. Carroll, “Script Doctor,” *F(r)iction*, 2024. Forthcoming publication.

⁵³ Audrey T. Carroll, *Parts of Speech: A Disabled Dictionary* (Alien Buddha Press), 2023, <https://alienbuddhapress.wordpress.com/2023/04/09/spotlight-parts-of-speech-a-disabled-dictionary-by-audrey-t-carroll/>.

oversimplifies pain into a number from one to ten, as though the specificities of each number are clear to every patient and/or medical professional in the same way, and as if pain is a universally-agreed-upon experience for every person in every body. Huber uses this to convey different sorts of pain—from being “[i]n a sort of grinding, background-noise, world-clenching box of pain just beneath the edge of my consciousness,”⁵⁴ to “[e]verything is so beautiful and precious because I might die soon. I love that lampshade so very much,”⁵⁵ to “[...] Words are hard. My name is... something? Whatever. ‘Name.’”⁵⁶ This scale, rather than going from one to ten, reaches twenty-one. Each level is extremely particular; Huber uses the memoiristic elements to narrate her pain at each very specific level, which highlights the absurdity of the “1–10” scale with no further explanation required.

In “Note,” a section of *My Body is a Book of Rules*, Elissa Washuta similarly co-opts something from the medical field. Here, the document is a letter from a psychiatrist, which is noted as being edited by Washuta. She also incorporates other forms throughout *My Body is a Book of Rules*; for example, after some more traditional prosaic preamble in “Please Him,” the essay turns into a side-by-side of religious commandments and questions from *Cosmo*. Similarly, Huber is not confined to simply one form—or even one experimental form—in her deviation from otherwise traditional narratives in *Pain Woman Takes Your Keys*. As a craft approach that will later be explored in Leah Lakshmi Piepzna-Samarasinha’s *Dirty River*, Huber’s essays, such as “From Inside the Egg,” turn into sections of poetry, lines broken and playing with marginal alignments.

In the essay “Even If You Can’t See It: Invisible Disability and Neurodiversity,” Sejal A. Shah takes documentation and hybridity in a slightly different direction. Instead of co-opting an established formal document and rewriting the script from a crippled⁵⁷ perspective, Shah makes use of end notes. In this way,

the essay blends scholarly elements with creative ones. Some of these end notes clarify intertextuality, such as with the incorporation of a lyric essay/flash fiction Shah herself wrote. Others are more critical, sourcing the disability community’s use of the term “Spoon Theory”⁵⁸ and texts like Margaret Price’s *Mad at School: Rhetorics of Mental Disability and Academic Life*. This kind of tracing to other genres, as well as critical thinking about disability, is perhaps especially helpful to an abled audience. Simultaneously the style of hybridity that relies on end notes allows the narrative to continue without necessarily disrupting one’s reading. It is therefore possible for a disabled reader who is, for instance, already familiar with Spoon Theory, to continue reading without pausing to examine the end note in its entirety. Or, alternatively, it could work as a way to welcome newer disabled/ill community members into the discourse without forcing them to do the research entirely on their own. This takes on a kind of community-building/mentorship aspect that may otherwise feel unavailable to newly disabled/ill people.

Disabled and chronically ill people are often assumed to be unable to tell their own stories, or not skilled enough to be up to the task. This assumption, while often not discussed in direct terms, is implicitly understood at the cultural level. It is obvious when people talk to caretakers as if disabled people are not present; it is obvious when medical professionals refuse to take patients seriously, or in legal and governmental contexts where loopholes enable institutions not to provide access to disabled people. Memoir, as a genre, is “[i]n direct dialogue with, and part of, social movements agitating for cultural and legal change,”⁵⁹ and can reflect this in dialogue of choices of form. Hybridity and awareness of techniques outside of the essay can inflect how memoir might take shape. This could lead to a combination of processes that includes the rewriting of medical documentation. Erasure, for instance, is a form most common in poetry, but can

⁵⁴ Sonya Huber, *Pain Woman Takes Your Keys, and Other Essays from a Nervous System* (Lincoln, Nebraska: University of Nebraska, 2017), 155.

⁵⁵ Huber, *Pain Woman Takes Your Keys*, 156.

⁵⁶ Huber, *Pain Woman Takes Your Keys*, 157.

⁵⁷ See <https://cdsc.umn.edu/cds/terms> on the usage of the term “crip” and related vocabulary.

⁵⁸ For further information on “spoon theory,” see: <https://www.washingtonpost.com/wellness/2023/01/14/spoon-theory-chronic-illness-spoonie/>.

⁵⁹ Hall, “Disability Life Writing,” 133.

easily be used in memoir as well. The process likely looks like trying to find truth—personal truth, or communal truth—in the document used as the basis for erasure. This can operate as an act of reclamation for a disabled/chronically ill writer if they take the opportunity to recontextualise medical, legal, and/or governmental documents. Such a formal choice causes many questions to arise without posing them directly in the text: What are the true effects of these documents? How do these documents affect the emotional lives of disabled and ill people? What do these documents really mean if you read between the lines? What is a disabled/ill person’s perspective on the coded language these documents use and how they impact disabled/ill people’s lives? Erasure of these particular documents is only one of many possibilities for the hybrid and experimental approach, but it does allow for one method of reclamation that disabled/ill writers can potentially leverage in.

Poetic Narration & Crip Time

The lyric essay, as a form, offers a strong opportunity to centre voice in all its rhythmic specificity. It is possibly the most common way to blend memoiristic elements with poetic elements. Zoë Bossiere and Erica Trabold write about the lyric essay in “Writing from the Margins: On the Origins and Development of the Lyric Essay,” that this form

[i]s fluid, able to occupy both marginal and centre spaces [...] uniquely suited to telling stories on the writer’s terms, without losing sight of where the writer comes from, and the audiences they are writing toward. When we tell the stories of our lives—especially when those stories challenge assumptions about who we are—it is an act of resistance.”⁶⁰

This fluidity allows the lyric essay to take the shape of the container of the writer’s experiences, “telling stories on the writer’s terms.” It grounds the voice in these lived experiences, asserting the writer’s right—

the disabled/ill person’s right—to tell their own story their own way. This is, as Bossiere and Trabold phrase it, an “act of resistance.” It is resistance against the notion that we are voiceless, resistance against the ableist assumptions of who we are and what we can do, and resistance against the dictation that disabled/ill stories need to be narrated in expected ways in order to be respected and listened to.

The last of these is something which disabled/ill people—as storytellers on and off the page—face every day. How we convey symptoms orally and bodily, for instance, dictates the care we receive and the respect we’re granted. Our stories are received in particular ways depending on our embodiments, especially in the sociocultural context of intersectional vectors of marginalization and oppression. In some ways, all disabled/ill people are storytellers in their own right, navigating audience expectations and genre constraints as we attempt to have our basic needs met. The lyric essay rejects this imposition of how we’re “allowed” to tell stories—clear narratives, simple language, straightforward chronologies—and leans into our poetic abilities at the same time.

At first glance, Leah Lakshmi Piepzna-Samarasinha’s “The Last Time I Went Home for Christmas” might be a narrative like any other.⁶¹ However, it is possible to see a lack of fidelity to linearity pretty early on, an expression of “crip time.” (Alison Kafer muses in *Feminist, Queer, Crip*, about how “[e]xploring disability in time also includes speculation on temporalities of disability: how might disability affect one’s orientation to time?”⁶²) The first sentence that Piepzna-Samarasinha writes in “The Last Time I Went Home for Christmas” is a result, a conclusion. The second paragraph is a rationale with a backstory. Then we get a line that sets the scene, a context, before Piepzna-Samarasinha’s age is given in the same paragraph as a retrospective voice (“now that I am no longer twenty-one”⁶³). After this opening establishes a kind of when and why (at the age twenty-

⁶⁰ Zoë Bossiere and Erica Trabold, “Writing From the Margins: On the Origins and Development of the Lyric Essay,” *Literary Hub*, published April 10, 2023, <https://lithub.com/writing-from-the-margins-on-the-origins-and-development-of-the-lyric-essay/>.

⁶¹ Leah Lakshmi Piepzna-Samarasinha, “The Last Time I Went Home for Christmas,” *Dirty River: A Queer Femme of Color Dreaming Her Way Home*, (Vancouver: Arsenal Pulp Press, 2016), chapter 11, Kindle.

⁶² Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: University of Indiana Press, 2013), 26.

⁶³ Piepzna-Samarasinha, *Dirty River*, chapter 11, Kindle.

one, at Christmas, because of lice and dreadlocks), Piepzna-Samarasinha moves into what she labels as *Story Version One*, which gives the two-years-prior context of the dreadlocks, a choice that includes having taken drugs first and immediate regret after. *Story Version One* provides broader cultural context, too, about appropriation. *Story Version Two* picks up at the end of the opening section, then reminisces on how it reminds Piepzna-Samarasinha of her childhood, of how the way her white mother treats her hair feels wrong to her, including a broader cultural context of anti-Blackness and speculative elements as to her mother's disappointment in her. This section ends in abrupt verse—line broken and with little capitalisation. The final section, labelled *Backstory*, returns to when Piepzna-Samarasinha is eleven or twelve, the first time she notices her hair is curly—each sentence is given its own line break, until eventually the chapter/essay ends on an italicised stanza that is even more heavily broken in lines.

Huber writes that “[v]oices broaden and strengthen and proliferate when they are heard, responded to, and encouraged, and they wither in self-protection and hunger when they aren't listened to. Or if they're ignored and dismissed, they learn to explode and boom to make some space.”⁶⁴ Again, leaning on a cross-genre knowledge with poetry, playing with space on the page can be a way to “take up space.” For the marginalized, this can be a very literal way to centre our identities, to break free of the sides of the pages that we have been relegated to, instead breathing where it feels sensical to us, or condensing in other places.

Mimesis & Audience

As Huber points out, “writing about something traumatic in a way that invites the reader into the experiences and adds reflection and meaning is extremely challenging.”⁶⁵ Some readers may feel, however fairly or unfairly, that reading about illness/disability is too sad or depressing. This may turn them off from reading these narratives altogether, which

undermines writers whose aim is to use their literature as a bridge between their own life experiences and abled people's life experiences. When our experiences are dismissed or ignored because they include unpleasantness, then writing risks its potential to engender empathy.

There is nuance here, certainly: as already mentioned, disabled/ill writers should not be beholden to the frameworks imposed on them by abled people. While this may not work for every reader (no technique does), there is a mimetic approach to consider here. Some brains, for a host of different reasons, process and/or produce narratives in fragments. This may turn into a text that is something like Piepzna-Samarasinha's “The Last Time I Went Home for Christmas,” to highlight a previous example. A fragmentary style of brain processing can be imitated on the page, though it is, to use Huber's language, “extremely challenging”⁶⁶ to have this be engaging to a reader, especially a reader who lacks first-hand experience with such a way of thinking. The choices for fragments can vary with sentence-to-sentence shifts, dipping back and forth in a timeline that seems out of order; changes from paragraph to paragraph in topics, following thoughts in seemingly random directions that make some kind of an associative sense as experienced by the writer. This can also ease the writing process for some disabled/ill writers, while removing the pressure of “conventional narrative scripts.”⁶⁷ Such relief may come through in the narrative fluidity of the text.

Conclusion

Experimental forms are by no means the only method that disabled writers have at their disposal. Strong narratives have been constructed about these topics in more traditional forms. It would do no good to say that we shouldn't pigeon-hole disabled/ill writers into what is considered a more traditional style of writing, because they should instead be pigeon-holed into this other style of writing. In part, some of the discussion of possibilities here is born of my

⁶⁴ Huber, *Voice First*, 73.

⁶⁵ Huber, *Voice First*, 86.

⁶⁶ Huber, *Voice First*, 86.

⁶⁷ Hall, “Disability Life Writing,” 132.

personal affinity for queering narrative, for seeing the ways that we might be able to disrupt and generate in innovative processes. But it is worth exploring why disabled/ill writers may opt for an approach that may seem unexpected. The expected has rarely, if ever, served the disabled and the ill; sometimes, working outside of the expected seems like the most productive way to take up space, to make our voices heard, and to reclaim the stories that we've been dissuaded from sharing for so long.



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