Work and chronic illness in contemporary feminist illness writing 2015-2022

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Work and Chronic Illness in Contemporary Feminist Illness Writing 2015-2022

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Declaration

I confirm that the work presented in this thesis is my own.

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Vedbæk, 5th June 2023

Abstract

This thesis looks at engagement with the concept of work in UK and US life-writing about chronic illness between 2015 and 2022. In texts by writers including Anne Boyer, Johanna Hedva, Carolyn Lazard, Sonya Huber, Alice Hattrick, Dodie Bellamy, and Porochista Khakpour, the experience of living with chronic illness is shaped by and against neoliberal capitalism and contemporary work culture. I call this grouping *contemporary feminist illness writing*. These writers do not show illness as the antithesis to work but instead render visible the ways in which illness and work compound each other. With a rise in 'patient work' and an increasingly active sick role, illness entails administrative, reproductive, and investigative labour. I demonstrate how contemporary writers draw on intersectional feminist and leftist political thought in their textual experiments to represent how incapacity and pain intersect with effort and skill in the experience of chronic illness. I argue that work is not just a central theme in this grouping but that it actively informs its textual strategies. Writers play with intensifying and withdrawing labour and with appropriating and subverting medical and work genres like the list, the case history, the e-mail, and various forms of accessibility documents. I argue that engagement with the concept of work marks a departure from earlier generations of illness writing and the teleological narratives of self-development described by critics including Anne Hunsaker Hawkins and Arthur Frank. Building on recent critical accounts of the neoliberal aspects of teleological narratives, I contend that contemporary feminist illness writers use alternative, non-teleological narrative forms. Their poetics of impairment emphasizes imperfection, collective thinking, and subjects in a variety of differently-capacitated states. Drawing lines back to the history of illness writing, I argue that writing on the ill bodymind continues to be a resource for imagining alternatives to the 'good' worker-citizen.

Acknowledgments

When I think of the five years this project has taken, I think of the many places I have written this thesis in. Each have imparted their own particular flavour to the finished dish: the generous academic community of Birkbeck's Department of English, Theatre and Creative Writing in Gordon Square; the sun and zipping hummingbirds in the botanical gardens of The Huntington Library in California where I held an IPS fellowship; the ocean view from my office at the Louisiana Museum of Modern Art in Humlebæk; the 400 year-old culture of communal living at Regensen in Copenhagen; and the delicious scents at dinnertime in the now mostly-demolished Woodberry Estate in Manor House, London, to name just a few.

I could not have written this thesis without the support of many wonderful and inspiring scholars. I am grateful to my supervisors, Peter Fifield and Jo Winning, for guiding me through the long process with so much wisdom and care. I also thank the teachers and tutors who have taught me through the 24 years of schooling which this thesis concludes, not least Bolette Lentz, Laura Ashe, Emily Coit, and Susan Valladares. My thinking has likewise been shaped and sharpened through conversations with brilliant friends and academics including Lucy Brookes, Jacob Gracie-Burrow, E.K. Myerson, James Rákóczi, and George Townsend.

Being a whole person throughout such a long and difficult process can be challenging; to the degree that I managed, I also thank the support and friendship of Laura, Victoria, David, Mikkel, Brigette, Mari, Matilde, Klara, Line, Giulia, Rebecca, and John. Lastly, I cannot overstate the support of my closest family: my brother Johan, my father Mogens, and my mother Janne, who also gave me a place to live in the sometimes rather long gaps between sublets, short rental contracts, and international moves.

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List of Illustrations

Introduction: The 'Poet-Economist' of Illness

In her essay 'Woman Sitting at the Machine' (2018), Anne Boyer writes:

> On May Day I write a poem:
>
> > Cancer is work,
> > but work is work, too.
>
> You do the work of being sick, the work of trying not to be sick anymore, the work of going to work while sick, the work of what is unpaid work, also.[1]

Is illness the antithesis of work? Illness—as opposed to laziness, unproductivity, or incapacity—is widely understood as a sanctioned exception from normal responsibilities and work, as Talcott Parsons described in his theorisation of the 'sick role' in the 1950s.[2] But Boyer's narrator emphasises that illness, in her case cancer and the long-term debilitating consequences of cancer treatment, is not the opposite of work. In fact, illness is a profoundly active and exhausting process, in which different types of work and labour compound each other. She positions being ill as a type of work, alongside going through treatment, having to carry on with a job at the same time, and the extra effort of doing that job while ill.

Boyer's narrator seizes on a discourse of describing illness as work which is ubiquitous among illness writers and advocates. In articles, Martha Paschall-Boykin explains why 'Living With Chronic Illness Is a Full-Time Job' and Alex Haagaard describes getting ill as a matter of having to 'stop working in my chosen field so that I could begin working full-time as a patient'.[3] In recent memoirs, the writers Sonya Huber, Abby Norman, and Porochista Khakpour all describe living with their very

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[1] Anne Boyer, *A Handbook of Disappointed Fate* (Brooklyn: Ugly Duckling Presse, 2018), p. 171.

[2] Talcott Parsons, *The Social System* (Psychology Press, 1991).

[3] Martha Paschall-Boykin, 'Living With Chronic Illness Is a Full-Time Job', *Longevity*, 2018 <https://vocal.media/longevity/living-with-chronic-illness-is-a-full-time-job> [accessed 26 February 2020]; Alex Haagaard, 'What It's Like Living and Working With a Chronic Illness', *The Muse* <https://www.themuse.com/advice/working-living-with-a-chronic-illness> [accessed 26 February 2020].

different chronic illnesses—rheumatoid arthritis, endometriosis, and Lyme disease, respectively—as having a full-time job.[4] Boyer's narrator pushes these metaphors one step further. Symbolically or literally written on May Day, also known as International Workers' Day, the poem suggests the inception of a new section of the labour movement. If illness is work, should the ill unionise?

Illness and work are not mutually exclusive for most people living with chronic illness, an estimated 40 per cent of the US population.[5] People with chronic illness are only three percent less likely to be in full-time employment than the US average, and those who are employed work the same amount of hours.[6] The rise in casualisation, zero-hour contracts, and cuts to public social security have most likely only exacerbated the co-existence of illness and work in many people's lives, with some jobs causing or aggravating illness. Moreover, public health research has shown that the tasks asked of patients and their support networks (e.g., in relation to paperwork, the monitoring of conditions, self-administering treatments, liaising between providers) have steadily risen over the last six decades.[7] These trends all exacerbate already-existing inequalities, as the most marginalised populations are

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[4] Sonya Huber, *Pain Woman Takes Your Keys, and Other Essays from a Nervous System* (Lincoln: University of Nebraska Press, 2017), p. 31; Abby Norman, *Ask Me About My Uterus: A Quest to Make Doctors Believe in Women's Pain* (New York City, NY: Nation Books, 2018), p. 182; Porochista Khakpour, *Sick: A Memoir* (Edinburgh: Canongate, 2018), p. 174.

[5] Wullianallur Raghupathi and Viju Raghupathi, 'An Empirical Study of Chronic Diseases in the United States: A Visual Analytics Approach to Public Health', *International Journal of Environmental Research and Public Health*, 15.3 (2018) <https://doi.org/10.3390/ijerph15030431>.

[6] Brian W. Ward, 'Multiple Chronic Conditions and Labor Force Outcomes: A Population Study of U.S. Adults', *American Journal of Industrial Medicine*, 58.9 (2015), 943–54 <https://doi.org/10.1002/ajim.22439>. This study only included the 10 most common chronic health conditions in the US: hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, weak/failing kidneys, current asthma, and chronic obstructive pulmonary disease.

[7] Carl R. May and others, 'Rethinking the Patient: Using Burden of Treatment Theory to Understand the Changing Dynamics of Illness', *BMC Health Services Research*, 14.1 (2014), 281 <https://doi.org/10.1186/1472-6963-14-281>.

more likely to get seriously ill and less likely to have healthcare and the time, means, and support to undertake the extra administrative work entailed by illness.[8]

However, Boyer's poem positions illness as not just one among many types of work, but as a *primary* form of work. Had the lines been the other way round—work is work, but cancer is work, too—the statement would have been more familiar. We are used to the concept of work being invoked to draw attention to the strenuousness of something, as well as in the feminist concepts of *emotional labour*, *affective labour*, *reproductive labour* and *the second shift*, coined to name and resist the unpaid efforts in the home, social relationships, and workplaces which are disproportionately undertaken by women.[9] But in the poem, the lines are arranged so that the claim about cancer being work comes first. The claim is allowed to stand alone before being complicated by the reality of other kinds of work—presumably employed work—existing alongside it. This suggests that work is not just an important framework for understanding the contemporary experience of illness in the US (as emphasised by the other writers and advocates using it as a metaphor), but that illness can tell us something about work too.

In 'Woman Sitting at the Machine', the imbrication of illness and work leads the narrator to wish for an 'alien […] poet-economist' who can figure out 'how [her] pain creates profit'.[10] This wish testifies to the pervasiveness of neoliberal ideology, described by theorists as a type of rationality in which the model of 'the market' is extended to other areas of life, including the previously 'noneconomic spheres' such

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[8] See e.g., Peter Salmon and George M Hall, 'Patient Empowerment or the Emperor's New Clothes', *Journal of the Royal Society of Medicine*, 97.2 (2004), 53–56; Collette Sosnowy, 'Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise', *Societies*, 4.2 (2014), 316–29 <https://doi.org/10.3390/soc4020316>.

[9] Susan Ferguson, *Women and Work: Feminism, Labour, and Social Reproduction* (Pluto Press, 2020) <https://doi.org/10.2307/j.ctvs09qm0>.

[10] Boyer, *A Handbook of Disappointed Fate*, p. 172.

as ‘education, health, fitness, family life, or neighborhood’.[11] Under neoliberalism, economics have come to be seen as a primary science for understanding human behaviour and interaction; economists, as Sylvia Wynter observes, now have the status of a ‘secular priesthood’.[12] In 1821, Percy Bysshe Shelley claimed that poets were ‘the unacknowledged legislators of the world’, but in the world Boyer is inhabiting, the poet cannot speak truth without recourse to economics.[13] It has become almost impossible to conceptualise life outside a neoliberal, economic framework.

This thesis is an attempt to see what happens when following Boyer’s call for a ‘poet-economist’ of illness. Many contemporary writers living with chronic illness inhabit a version of this position, intertwining economic and literary frameworks to understand the contemporary experience of illness. This thesis surveys the increase in texts of this category, which I term *contemporary feminist illness writing* because engagement with feminist and leftist economics are at the centre of their political and literary aims. By exploring what it means to be chronically ill under neoliberal capitalism, and wrestling with categories and frameworks that valorise ‘productivity,’ a quality that is often unattainable from a point of illness and debility, Boyer and other contemporary writers challenge ideals of bodily and mental capacity. Boyer’s essay is exemplary of how this new wave of illness writing explores the ways in which health and unhealth are shaped by the political and economic ideologies of global capitalism, but also how writing from a position of

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[11] Wendy Brown, *Undoing the Demos: Neoliberalism’s Stealth Revolution* (New York: Zone Books – MIT, 2015), pp. 30–31.

[12] Sylvia Wynter and Katherine McKittrick, ‘Unparalleled Catastrophe for Our Species? Or, to Give Humanness a Different Future: Conversations’, in *Sylvia Wynter: On Being Human as Praxis*, ed. by Katherine McKittrick (Durham: Duke University Press, 2015), pp. 9–89 (p. 26).

[13] Percy Bysshe Shelley, *A Defence of Poetry* (The Bobbs-Merrill Company, 1904), p. 90 <http://archive.org/details/defenceofpoetry012235mbp> [accessed 19 May 2023].

illness can have its own kind of political power. I argue that especially positioning the sick woman as a type of 'worker' becomes a crucial step in claiming political agency. After decades of declining approval, labour organising is now having a popular resurgence.[14] This has been prefigured in illness writing, which borrows heavily from the labour movement's forms and strategies. To be a worker is to be seen as someone who contributes to society, a citizen who takes responsibility for the society they live in: it confers legitimacy through already established hierarchies of value. To be a unionised worker is to have a seat at the table. Describing the sick woman as a worker is a way to stake a claim to political legitimacy and societal value.

Contemporary feminist illness writing

I describe the grouping of recent texts about the political and economic dimensions of illness as contemporary feminist illness writing. I take these to be literary texts written about personal experiences of illness published since about 2015 in the US and the UK, informed by intersectional feminist theory and leftist political engagement. 2015 is chosen as a starting point for the thesis because this year saw the publication or presentation of important texts including Dodie Bellamy's *When the Sick Rule the World* (2015), Amy Berkowitz's *Tender Points* (2015), and Johanna Hedva's 'My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want it to Matter Politically' (2015), subsequently published as 'Sick Woman Theory' (2016). In the essay 'Tender Theory' (2016), Boyer provided the first theorisation of these texts as connected; in her words, they inaugurate a

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[14] Justin McCarthy, 'U.S. Approval of Labor Unions at Highest Point Since 1965', *Gallup*, 30 August 2022 <https://news.gallup.com/poll/398303/approval-labor-unions-highest-point-1965.aspx> [accessed 19 May 2023].

'collective project of important thinking about the sick feminized body under current conditions'.[15]

I focus on writers working in English, primarily in the US and the UK, for reason of scope and because writers working in these two countries form a particularly distinct network. The fact of a deeply intertwined literary community and publishing sphere means that writers build on each other across the national boundaries. This is particularly pronounced among the writers that engage with feminist thinking and online chronic illness communities. That this network of writers precedes and exists independently of this thesis can be seen in the large citational apparatuses included in many of the texts I analyse, citing other authors also included. It is also apparent in a recent canon-building project, Kaiya Waerea's 'Read Sick Writers'. For this project, which has already had three iterations, Waerea sold various clothing items with a bibliography of 'sick writers' and their most important texts printed on them (see *Figure 1*). This bibliography includes many of the primary texts analysed in this thesis. I argue that the deliberate engagement with other texts forms a key part of the grouping and its unionising aesthetic; a strategy to accommodate debility through distributed and collaborative work and shared authorship (see Chapter 5).

[Image removed in this version]

Figure 1: Kaiya Waerea, *Read Sick Writers*, third edition. From Waerea's Instagram account, @kaiyawaerea [accessed 19/05/2023]. Authors included are Johanna Hedva, Charlotte Perkins Gilman, Kate Zambreno, Dodie Bellamy, Alison Kafer, Carolyn Lazard, Susan Sontag, Virginia Woolf, Elaine Scarry, Susan Wendell, Olivia Sudjic, Annemarie Mol, Leslie Jamiseon, Lucia Osborne-Crowley, Audre Lorde, Amy Berkowitz, Abi Palmer, Jenn Ashworth, Anne Boyer, Alice Hattrick, Leah Lakshmi Piepzna-Samarasinha, Sinead Gleeson, Eli Clare, and Catriona Morton.

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[15] Anne Boyer, 'Tender Theory', *The Poetry Foundation*, 2016 <https://www.poetryfoundation.org/harriet/2016/01/tender-theory-> [accessed 18 September 2019].

In contrast, taking 2022 as the end point follows the natural limitations of this thesis which is submitted in 2023. Writing in June 2023, there is no sign of an abatement in the publication of, or appetite for, political and feminist illness writing. However, between 2015 and 2022, the status of the texts has changed. Not only have many book-length publications been published in this time.[16] Since 2015, more than a dozen English-language magazines have been established specifically to provide platforms for politicized chronic illness and disability writing with an emphasis on publishing work by women, genderqueer, and non-binary creatives, attesting to a large community of writers and readers.[17] Within the literary world, a large number of events, exhibitions, special issues, and a newly founded prize, The Barbellion Prize, have consolidated the sense that a distinct movement is developing and that these works need to be read together.[18] The texts have had an influence that exceeds the literary field, with writers like Johanna Hedva, Anne Boyer, Carolyn Lazard, and Porochista Khakpour being credited for inciting a wider '*turn to health* in

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[16] Book-length literary investigations of the feminized, chronically ill body in the context of biomedical, political, economic and cultural inequalities include Leah Lakshmi Piepzna-Samarasinha's *Body Map* (2015), *Care Work* (2018), and *The Future is Disabled* (2022) Amy Berkowitz' *Tender Points* (2015), Sonya Huber's *Pain Woman Stole My Keys* (2017), Megan O'Rourke's *Sun in Days* (2017) and *The Invisible Kingdom* (2022), Kelly Davio's *It's Just Nerves* (2017), Liz Bowen's *Sugarblood* (2017), Porochista Khakpour's *Sick: A Memoir* (2018), Abby Norman's *Ask Me About My Uterus* (2018), Karen Havelin's *Please Read this Leaflet Carefully* (2019), Sinéad Gleeson's *Constellations* (2019), Jenn Ashworth's *Notes Made While Falling* (2019), Boyer's *A Handbook of Disappointed Fate* (2018) and *The Undying* (2019), Esmé Weijun Wang's *The Collected Schizophrenias* (2019), Abi Palmer's *Sanatorium* (2020), Alice Hattrick's *Ill Feelings* (2021), and Elinor Cleghorn's *Unwell Women* (2021), many of which have been critically acclaimed and commercially successful.

[17] See for example *Deaf Poets Society* (f. 2016), *Tiny Tim* (f. 2016), *Monstering Magazine* (f. 2017), *Blanket Sea* (f. 2018), *Spooniehacker* (f. 2018), *Ache* (f. 2019), and *SICK Magazine* (f. 2019), *Able Zine* (f. 2019), *Dubble Zine*, (f. 2019), *The Reluctant Spoonie* (f. 2020), *Look Deeper Zine* (f. 2020), *Bed Zine* (f. 2021), *Wishbone Words* (f. 2021), *Lassitude* (f. 2022), *Not Your Monolith* (f. 2022). See also the collective manifesto *Not Going Back to Normal* (2020) made in response to the covid-19 pandemic, encompassing 49 online artworks. <https://www.notgoingbacktonormal.com> [accessed 20 November 2020].

[18] Since 2016, feminist magazines including *Bitch Magazine* and *Triple Canopy* have run special issues or article series on women, pain, and chronic illness. A number of conferences including 'Sick Fest' (March 2016) and 'Sick Theories' (November 2018), have been organised to facilitate conversations on illness writing inspired by Hedva. See also exhibitions such as the Welcome Collection's *Jo Spence and Oreet Ashery* (dates, 2019) and the London-based Parrhesiades' *A Season of Cartesian Weeping* (2019).

contemporary art'.[19] As can also be seen in Waerea's project, selling what is essentially merchandise for the literary grouping, political and feminist illness writing has become more of a 'brand': a unified body of works with commercial success and commodity status. The grouping has developed its own distinct and recognisable form, something also pointed out by detractors, who lament the popularity and predictability of this 'genre of affliction'.[20]

Along with the change in status, the concerns and objectives of the texts have also changed. Texts published in the earlier part of the period I analyse respond to and challenge an earlier tradition of illness memoir focused on the individual's journey in overcoming illness (see Chapter 1). The authors write from the margins, positioning the texts as politically subversive by virtue of representing something which was so rarely represented without castigation: the chronically ill feminized body. Moreover, they represent the experience of chronic illness without espousing narratives of personal development or growth, seeking to challenge both the idealisation of health and the project of global neoliberal capitalism. The texts written at the end of the period do this too, but have also started to reflect on the success and proliferation of feminist illness writing. Hedva's recent essay, 'Why It's Taking So Long' (2022), for example, reflects on the consequences of chronic illness and disability suddenly becoming fashionable themes, moving from the margins towards assimilation into the mainstream (Chapter 4). Although this thesis focuses on texts written primarily within a period of 8 years, this period therefore oversees a particular development: the formation of contemporary feminist illness writing as a recognisable and significant grouping in contemporary literature.

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[19] Barbara Rodriguez Munoz, *Health*, 1st edition (London: Whitechapel Gallery, 2020), p. 13.

[20] Houman Barekat, 'The Genre of Affliction', *Gawker*, 12 May 2022 <https://www.gawker.com/culture/the-genre-of-affliction> [accessed 8 June 2022].

This body of texts have been—and continue to be—written at a time in which issues of (un)health are at the centre of political strife. In the US, late 2015 saw increasing polarisation as well as disappointment on the left with the achievements of the Obama administration. With the election of Donald Trump as President in 2016, access to healthcare came under threat as Trump promised to repeal the Affordable Care Act of 2010 (ACA, also known as Obamacare) which had halved the number of uninsured people in the population. While this was never completed, funding cuts, the repeal of the ACA's individual mandate penalty, and other changes to the system resulted in increased levels of uninsurance due to higher prices and more barriers to entry.[21] Moreover, reproductive rights came under threat, culminating in the overturning of abortion rights through *Roe v. Wade* in 2022 by Supreme Court judges appointed by the Trump administration. In the UK, austerity politics enforced by the Conservative government have continued the pressure on the National Health Service (NHS).[22] Moreover, the Covid-19 pandemic which began in 2020 led to high mortality rates and many people contending with Long Covid and other ensuing long-term conditions in both countries. Politicians and economists made it clear that some bodies were more 'grievable' than others, as analysed by Judith Butler.[23] The lives of older people and people with chronic health conditions were seen as secondary to the objectives of getting the 'healthy' population back to work. Deaths in these populations were reported separately, suggesting less

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[21] Adam Gaffney, David Himmelstein, and Steffie Woolhandler, 'How Much Has The Number of Uninsured Risen Since 2016 — And At What Cost To Health And Life?', *Health Affairs Forefront*, 2020 <https://doi.org/10.1377/forefront.20201027.770793>.

[22] Kirsteen Macdonald and Heather May Morgan, 'The Impact of Austerity on Disabled, Elderly and Immigrants in the United Kingdom: A Literature Review', *Disability & Society*, 36.7 (2021), 1125–47 <https://doi.org/10.1080/09687599.2020.1779036>.

[23] Judith Butler, 'Capitalism Has Its Limits', *Verso Blog*, 2020 <https://www.versobooks.com/blogs/4603-capitalism-has-its-limits> [accessed 28 November 2020].

importance, and those with heightened risks were told to isolate for long periods so the rest of the society could function 'normally'.

It is therefore not surprising that this period has seen an increase in literary writing dealing with the politics and economics of health, often intersecting with issues of race, class, gender, and healthcare for trans people, all issues that have been at the centre of public debates. Especially important in the US and the UK have been the resurgence of the Black Lives Matter movement and the championing of trans rights in the face of attacks from the political right. The influence of these protest movements is crucial for contemporary feminist illness writing. Not only because many significant texts are written by trans-, nonbinary, and genderfluid writers and writers of colour, but because the Black Lives Matter movement has brought more attention to the inequalities which exist in healthcare.[24] It has become clear that illness is a profoundly political issue. This can also be seen in how anti-trans sentiment has often centred on arguments that trans people are groomers or other kinds of sexual predators.[25] These discourses make clear that conceptualisations and invocations of *sickness* exceed the medical domain. You do not have to be unwell to be perceived as 'sick', as the history of prejudice and discrimination against queer people demonstrates.[26] This shows how much is at stake politically, economically, and morally in the demarcation of health versus unhealth.

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[24] E. J. Sobo, Helen Lambert, and Corliss D. Heath, 'More than a Teachable Moment: Black Lives Matter', *Anthropology & Medicine*, 27.3 (2020), 243–48 <https://doi.org/10.1080/13648470.2020.1783054>; Kathomi Gatwiri, Darlene Rotumah, and Elizabeth Rix, 'BlackLivesMatter in Healthcare: Racism and Implications for Health Inequity among Aboriginal and Torres Strait Islander Peoples in Australia', *International Journal of Environmental Research and Public Health*, 18.9 (2021), 4399–4410 <https://doi.org/10.3390/ijerph18094399>.

[25] V. Jo Hsu, 'Irreducible Damage: The Affective Drift of Race, Gender, and Disability in Anti-Trans Rhetorics', *Rhetoric Society Quarterly*, 52.1 (2022), 62–77 <https://doi.org/10.1080/02773945.2021.1990381>.

[26] For more about the medical treatment of homosexuality which went on until shockingly recently in the UK and the US, and still is ongoing in other parts of the world, see e.g. Glenn Smith, Annie Bartlett, and Michael King, 'Treatments of Homosexuality in Britain since the 1950s—an Oral

Chronic illness and work

I analyse the political project of these texts especially as it relates to the conceptualisation of *work* and *labour*. To do so, I situate the texts within the other contemporary movements and bodies of thought they engage with: intersectional feminism, anti-ableism, anti-capitalism, and post-work theory. Under neoliberal cultural norms, in which working is often synonymous with having value, I argue that contemporary feminist illness writing demonstrates the value of thinking with illness and debility. With health and productivity as societal ideals, becoming ill can feel like being turned into 'spoilage and waste', as Kelly Davio writes.[27] Similarly, the author Esme Weijun Wang, who lives with multiple chronic illnesses, observes: 'in a society that holds productivity as unequivocally good, to do less feels like a moral failing'.[28] Chronic illness is the clearest deviance from expectations of health and sanity as those who are chronically ill are living embodiments that illness can be an ongoing state. Typically, no degree of effort or persistence with trying new treatments and strategies lead to a cure. Chronic illness therefore exemplifies the experience of failing to live up to societal ideals to always produce, earn, create, and grow. Ruth Wilson Gilmore describes how the ill and disabled are part of the 'surplus' population: a category constructed to effectively be the Other to capitalism's valued (productive, enterprising, individual) subject.[29] As Corinne Lajoie and Emily Douglas suggest, 'sickness' captures a more general sense of being

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History: The Experience of Patients', *BMJ : British Medical Journal*, 328.7437 (2004), 427 <https://doi.org/10.1136/bmj.37984.442419.EE>.

[27] Kelly Davio, *It's Just Nerves: Notes on a Disability* (Minneapolis: Squares & Rebels, 2017), p. 94.

[28] Esmé Weijun Wang, 'I'm Chronically Ill and Afraid of Being Lazy', *ELLE*, 2016 <https://www.elle.com/life-love/a35930/chronically-ill-afraid-lazy/> [accessed 21 June 2020].

[29] Ruth Wilson Gilmore, *Golden Gulag: Prisons, Surplus, and Opposition in Globalizing California* (Berkeley and Los Angeles: University of California Press, 2007).

‘out of synch with dominant expectations of sanity and productivity: sick as deviance from the norm and as a wilful refusal to be well, if “being well” mean[s] falling in line’.[30]

In this thesis, I contend that by challenging fundamental norms related to health and work, chronically ill writers can help us rethink what and who has value. Reading a selection of exemplary texts by writers including Anne Boyer, Johanna Hedva, Carolyn Lazard, Porochista Khakpour, Alice Hattrick, Sonya Huber, Leah Lakshmi Piepzna-Samarasinha, Abby Norman, Dodie Bellamy, Kaiya Waerea, and Jane Hartshorn, I argue that contemporary feminist illness writing challenges binaries of health/illness, ability/debility, and productivity/unproductivity in nuanced but also boldly defiant ways. This also has consequences for literary form, in the borrowing of textual and social forms traditionally belonging to labour activism such as the manifesto, the strike, and the union. I argue that by engaging with contemporary feminist illness writing, it is possible to look forward to more collective and inclusive forms of writing, including through written subjects which represent alternatives to the agentive, coherent, able, and neuro-typical subject which is culturally rewarded under neoliberal capitalism.

As in Boyer’s ‘Woman Sitting at the Machine’, in contemporary feminist illness writing the experience of chronic illness is continually positioned in relation to—shaped by and against—the concept of work. In this thesis, I am interested in how chronically ill writers represent, challenge, and rethink ideas of work and related concepts such as productivity, ability, and ‘capacity’. I argue that they do so using more traditional means such as form, metaphor, and genre. But I also find that

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[30] Corinne Lajoie and Emily Douglas, ‘Introduction: Critically Sick: New Phenomenologies of Illness, Madness, and Disability’, ed. by Corinne Lajoie and Emily Douglas, *Journal of Critical Phenomenology*, 3.2 (2020), p. 5 <https://journals.oregondigital.org/index.php/pjcp> [accessed 19 November 2020].

these texts rethink ideas of work by making changes to what surrounds and produces the texts: using collaborative authorship, alternative publishing models, and exploring the intersection between the literary and visual arts practices. Writers model new working practices and intervene into the workplaces of arts and literary institutions, demanding accessibility. And by exploring the alternative perspectives afforded by illness—recumbent, supported, momentarily liberated from goal-oriented and profit-generating temporal orientations—they consider what is missed in the forward gaze of what Virginia Woolf calls the 'army of the upright'.[31]

In contemporary feminist illness writing and artworks on chronic illness, the sick person as a worker is everywhere. Hedva's 'Sick Woman Theory' (2016) proposes the Sick Woman as a figure that can also stand in for the struggle of precarious workers. Memoirs such as Norman's *Ask Me About My Uterus* (2018), O'Rourke's *Sun in Days* (2017), and Khakpour's *Sick: A Memoir* (2018) demonstrate the labour that is demanded of patients. This labour relates to co-ordinating their own care and managing symptoms, but the texts also describe how they must undertake significant time and energy to research diagnoses and test treatments afterwards. Hannah Hodgson's speaker in 'Dear Body' (2018) portrays a Cartesian split between mind and body when the mind takes on the role of manager, threatening its organs with redundancy if they do not improve their performance, addressing them: 'Go home, / look over the job description / for a body. / Read it over – / let's start again tomorrow'.[32] Artworks in other genres also play with ideas of the chronically ill person as a worker, such as when the performance artist Martin O'Brien stages his own chronically ill body as a factory in *Mucus Factory* (2018) or

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[31] Virginia Woolf, 'On Being Ill', *The New Criterion*, January 1926, p. 36.
[32] Hannah Hodgson, 'Dear Body', *Wayleave Press*, 2018 <https://www.wayleavepress.co.uk/?page_id=1271> [accessed 11 February 2021].

the conceptual artist Daisy Cowley creates a union of chronically ill people, *The Union for the Useless* (2018—), replete with rules for membership and large textile union banners.[33] The intersection between work and illness, and particularly the borrowing of forms pertaining to labour activism, such as the union or the manifesto, are often entry points for nuanced discussions of constructions of citizenship, personal value, normative bodies, and contemporary work culture in texts by Huber, Lazard, Hedva, and Boyer. It can also be, as especially Hedva argues in 'Sick Woman Theory,' a site from which to build allegiances between those who are ill and other groups who are exploited or marginalised by capitalist ideals of productivity, with a goal of working together to dismantle global capitalism. For Hedva in this text, illness is already a mode of resistance to work, a type of strike.

As described above, the comparison between illness and work is ubiquitous in contemporary illness writing and among activist communities online. To create more clarity between the different definitions of work at play in this discourse, I use Hannah Arendt's distinction between work and labour in this thesis.[34] Arendt describes work as employment, whereas labour is effort that takes place outside an official relation of employment. According to these definitions, illness neither *is* nor *entails* work. Instead, it entails forms of labour. Managing chronic illness is reproductive work in the sense of daily work that must be undertaken to reproduce the body and its social relations (Chapter 2), but it may also necessitate investigative labour (Chapter 3) and activist labour to be accommodated (Chapter 4), as well as shape the ways in which work is done (Chapter 1).

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[33] Laura Daisy Cowley, *A Union For the Useless*, 2018 <https://www.lauradaisycowley.com/unionfortheuseless> [accessed 18 September 2020]; for Martin O'Brien, see e.g. 'Mucus Factory' (2011), in: 'Performances', *Martin O'Brien, Performance Artist* <https://www.martinobrienart.com/performance.html> [accessed 16 December 2020].

[34] Hannah Arendt, *The Human Condition* (Chicago: University of Chicago Press, 1970).

Recasting illness through the lens of work or labour can be a way of presenting it to others as a demanding and dynamic state that requires skill, attention, and ambition. This is an effective way of subverting negative ableist stereotypes of chronic illness: that chronic illness is a passive state that may be used as a cover for laziness or malingering. The claim that illness is a type of labour derives in part from a feminist activist practice founded with the *Wages for Housework* movement in the 1970s. Considering this movement, Kathi Weeks describes how an important aspect of drawing attention to reproductive and domestic labour as work was to insist 'on its demystification, de-romanticization, de-privatization, de-individualization, and of course, de-gendering'.[35] In this tradition, naming something as labour is a way to make visible efforts disproportionally undertaken by marginalised populations. Claiming that illness is a form of reproductive labour is a political claim intended to make an 'invisible' effort visible and reveal the relations of power which govern it, with a view to resisting them.

I argue that in engaging with conceptualisations of work and labour, contemporary feminist illness writers reveal and challenge (patriarchal, capitalist) power relations. The texts align themselves with an intersectional feminist critique developed within disability studies which positions ableism, the oppression along vectors of dis/ability, as a hegemonic practice through which racism, sexism, homophobia, transphobia, and many other types of oppression are enforced. Mia Mingus typifies this argument in the essay 'Moving Toward the Ugly: A Politic Beyond Desirability' (2011):

> Ableism set the stage for queer and trans people to be institutionalized as mentally disabled; for communities of color to be understood as less capable, smart and

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[35] George Souvlis and Kathi Weeks, 'Feminism and the Refusal of Work: An Interview with Kathi Weeks', *Political Critique*, 2017 <https://politicalcritique.org/world/2017/souvlis-weeks-feminism-marxism-work-interview/> [accessed 24 March 2023].

> intelligent, therefore ‘naturally’ fit for slave labor; for women’s bodies to be used to produce children, when, where and how men needed them; for people with disabilities to be seen as ‘disposable’ in a capitalist and exploitative culture because we are not seen as ‘productive;’ for immigrants to be thought of as a ‘disease’ that we must ‘cure’ because it is ‘weakening’ our country; for violence, cycles of poverty, lack of resources and war to be used as systematic tools to construct disability in communities and entire countries.[36]

Mingus describes how constructions of bodies and populations as more or less ‘capable’ are used to justify which kinds and what amounts of labour/work is expected of them, and what compensation they can expect for their work. The historical facts of enslavement and of women being classed as the property of men make clear that the extension of market logics to relationships and bodies is not a quality unique to neoliberalism.[37] In the words of Patty Berne, disability justice understands white supremacy and ableism to be ‘inextricably entwined, both forged in the crucible of colonial conquest and capitalist domination’.[38]

Following a social model of disability and illness, pathology is understood as deviance from a cultural norm rather than a fault in a particular body (the deficiency model of disability and illness). As Jasbir K. Puar observes, all neoliberal subjects are required to continually mark themselves as capable and productive worker-citizens, but this imperative has particular consequences for people living with a disability or illness.[39] Understandings of (un)health and (dis)ability are constructed

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[36] Mia Mingus, ‘Moving Toward the Ugly: A Politic Beyond Desirability’, *Leaving Evidence*, 2011 <https://leavingevidence.wordpress.com/2011/08/22/moving-toward-the-ugly-a-politic-beyond-desirability/> [accessed 28 November 2020].

[37] See work by Sylvia Wynter, Lisa Lowe, Jodi Melamed, Cedric Robinson, and Tanja Aho, ‘A Mad Critique of Anti-Neoliberalism: Sanism in Contemporary Left Thinking on Political Economy’, 2018, pp. 6–8 <http://ubir.buffalo.edu/xmlui/handle/10477/77919> [accessed 12 October 2020].

[38] Patty Berne, ‘Disability Justice - a Working Draft’, *Sins Invalid*, 2015 <https://www.sinsinvalid.org/blog/disability-justice-a-working-draft-by-patty-berne> [accessed 30 May 2023].

[39] Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham: Duke University Press Books, 2017).

dynamically in relation to paradigms of labour; as Puar writes, the parameters of the able subject shift

> as designations between productivity, vagrancy, deviancy, illness, and labor market relations have undergone transformations from subsistence work to waged labor to hypercapitalist modes of surplus accumulation and neoliberal subject formation.[40]

Analysing the labour undertaken by different bodies therefore becomes a way of understanding the power structures to which they are subjected. The refusal of labour, such as when those who are ill refuse to 'do their jobs as patients', borrowing a formulation from Arthur Frank, can be a way of challenging these power structures and make space for alternative ideas of health, capacity, and the distribution of resources.[41]

Contemporary feminist illness writing typically positions chronic illness as a privileged site from which to critique and resist global capitalism. As Lauren Berlant writes about Boyer's *The Undying*, debility related to chronic illness becomes a way into exploring 'a commons of suffering:' 'exhaustion as a universal experience of the contemporary—not just the sick, but the proletarianized, which includes an increasing mass of persons'.[42] Contemporary feminist illness writing documents what it means to be excluded from obtaining legitimacy through full-time work, an experience which is shared by many other groups in contemporary society. As Michael Denning writes, 'understandings built upon wage labour cannot, we are told, account for the reality lived by the most numerous and wretched of the world's population: those without wages, those indeed without even the hope of wages'.[43]

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[40] Puar, pp. xiv-xv.

[41] Arthur W. Frank, *The Wounded Storyteller* (Chicago: The University of Chicago Press, 1995), p. 93.

[42] Lauren Berlant, 'The Undying' <http://4columns.org/berlant-lauren/the-undying> [accessed 13 January 2020].

[43] Michael Denning, 'Wageless Life', *New Left Review*, 66, 2010, 79–97 (p. 79).

Although illness is only one among the many vectors that influence ‘wagelessness’ (others being e.g., race, gender, age, class, nationality, citizenship status), illness writing contributes to the exploration of what it means to be illegible under certain norms that govern contemporary society. While the illness writers whose works are analysed in this thesis are generally privileged in other ways—highly educated, citizens of powerful and affluent nations, and not so ill that they are completely unable to work or write—they explore ways of conceptualising the worth of populations excluded from neoliberal ideals related to work, something that has wider resonances.

Chronic illness

This thesis focuses on texts about chronic ‘physical’ or ‘somatic’ illness. People living with long-term conditions are a large and growing part of the population globally. As mentioned above, in America chronic illness is estimated to affect more than 40 per cent of the population and account for more than 70 per cent of the total healthcare spending.[44] In the UK, 36 per cent of the population reported a ‘long-standing illness or disability’ in 2013 and their treatment and care also account for about 70 per cent of acute and primary care budgets.[45] The definitions of what constitutes chronic disease vary greatly depending on which site, dictionary, medical authority, or organisation is consulted, to the extent that Stephanie Bernell and Steven W. Howard argue that the concept should never be used without

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[44] Raghupathi and Raghupathi.

[45] ‘Adult Health in Great Britain, 2013 - Office for National Statistics’ <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/compendium/opinionsandlifestylesurvey/2015-03-19/adulthealthingreatbritain2013> [accessed 12 February 2021]; ‘NHS England » House of Care – a Framework for Long Term Condition Care’ <https://www.england.nhs.uk/ourwork/clinical-policy/ltc/house-of-care/> [accessed 12 February 2021].

clarification.[46] I follow definitions issued by government agencies in the two countries that the thesis focuses on, the US and the UK. The US Center for Disease Control and Prevention (CDC) defines 'chronic disease' as 'conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both'.[47] This is similar to the definition of the UK term, 'long term physical health condition,' used by the NHS and the Office for National Statistics (ONS). This refers to 'a health problem' that both 'requires ongoing management over a period of years or decades' and 'cannot currently be cured but can be controlled with the use of medication and/or other therapies'.[48] While the incidence of chronic illness increases with age, the authors I read are comparatively young, between around 20 and 60 years of age at the publication of their texts. The writers belong to an age bracket in which employment is typically expected, which no doubt contributes to the theme of work being so prevalent in the texts.

Chronic disease typically encompasses both so-called 'physical' (or somatic) and 'mental' (or psychological) illnesses, but for the purposes of this thesis I focus on 'physical' illness i.e., illness understood as originating in the biological matter of the body. The primary reason for this is that there has been more academic investigation into literary texts dealing with mental illnesses such as depression, anxiety, schizophrenia, bipolar disease, and eating disorders than there has been into physical illnesses.[49] That being said, it is important to emphasise that the distinction

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[46] Stephanie Bernell and Steven W. Howard, 'Use Your Words Carefully: What Is a Chronic Disease?', *Frontiers in Public Health*, 4 (2016) <https://doi.org/10.3389/fpubh.2016.00159>.

[47] Centers for Disease Control and Prevention, 'About Chronic Diseases', *Cdc.Gov*, 2020 <https://www.cdc.gov/chronicdisease/about/index.htm> [accessed 16 December 2020].

[48] 'Long Term Physical Health Condition', *The NHS Data Model and Dictionary* (NHS DIgital) <https://datadictionary.nhs.uk/nhs_business_definitions/long_term_physical_health_condition.html> [accessed 16 December 2020].

[49] See e.g., Shoshana Felman, *Writing and Madness*, trans. by Martha Noel Evans (Palo Alto: Stanford University Press, 2003); *Literatures of Madness: Disability Studies and Mental Health*, ed. by Elizabeth J. Donaldson (Cham: Springer, 2018); Aho; Elizabeth Young, 'Memoirs: Rewriting the

between 'mental' and 'physical' illness is artificial. Most conditions and states, no matter their aetiology or symptomatic presentation, have both mental and physical dimensions, often inextricably bound up in each other. People living with chronic physical illness are more likely to have mental health conditions and vice versa.[50] The authors I look at in this thesis all have experience of living with at least one physical chronic illness, but most of them also live with mental health conditions, independent of, or linked to the physical illness. Throughout the thesis, however, I follow many of the writers in using the term 'bodymind' to acknowledge the interlinked complex of psyche and soma.

'Chronic illness' is the term most used among illness communities online and literary writers and platforms. It is deliberately more capacious than the more common medical terms, 'chronic disease' and 'chronic condition,' and I therefore prefer 'chronic illness' as a descriptor in this thesis. 'Chronic illness' does not involve gatekeeping by biomedical systems in the same way that the medical terms do, and it also emphasises the subjective experience of illness. In his influential distinction between 'illness,' 'disease,' and 'sickness' from 1975, Marshall Marinker proposes that 'illness' stands for the interior experience of unhealth as opposed to 'disease', which is exterior or measurable and for which an organic pathological basis is often known. Both are distinct from 'sickness', 'the external and public mode of unhealth' and 'a social role, a status, a negotiated position in the world'.[51] Hedva, Boyer, and other contemporary authors often favour the terms 'sick' and

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Social Construction of Mental Illness', *Narrative Inquiry*, 19.1 (2009), 52–68 <https://doi.org/10.1075/ni.19.1.04you>; Jeffrey Berman, *Mad Muse: The Mental Illness Memoir in a Writer's Life and Work* (Bingly: Emerald Group Publishing, 2019).

[50] Chris Naylor and others, *Long-Term Conditions and Mental Health: The Cost of Co-Morbidities* (London: The King's Fund, 2012) <http://www.kingsfund.org.uk/index.html> [accessed 27 April 2023].

[51] Marshall Marinker, 'Why Make People Patients?', *Journal of Medical Ethics*, 1.2 (1975), 81–84.

‘sickness’. This makes sense in terms of Marinker’s distinctions, in which ‘sickness’ describes the societal construction of unhealth; writers like Hedva and Boyer both reach beyond the personal to critique structural issues and ideologies at play in how illness is experienced. The concept of ‘sickness,’ as Corinne Lajoie and Emily Douglas write, emphasises how ‘experiences of bodily difference are framed by systems of power, exploitation, and oppression’.[52] I therefore use ‘chronic illness’ when analysing personal experiences of illness but follow the writers’ usage of ‘sickness’ when they are making arguments that reach across categories and suggest a broader applicability.

Context and contributions

The texts examined in this thesis are written by authors who draw on personal experiences living with chronic illness. In addition to drawing on feminist and leftist theory as described above, contemporary feminist illness writing often takes inspiration from contemporary life-writing more broadly, using collaborative, cross-genre, and activist approaches to destabilize literary forms and reassemble them in ways that better accommodate debility. By building literary forms that reproduce confusion, pain, and the ‘unfinished’ in different ways, I argue that contemporary feminist illness writing not only challenges neoliberal ideals of capacity, but also contributes significantly to the project of thinking the body otherwise. As part of challenging ideas of the capable individual, writers reject the structures of traditional illness narratives as well as conventions of single authorship and the coherent writing subject.

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[52] ‘Critically Sick: New Phenomenologies of Illness, Madness, and Disability’, ed. by Corinne Lajoie and Emily Douglas, *Journal of Critical Phenomenology*, 3.2 (2020), p. 6 <https://journals.oregondigital.org/index.php/pjcp> [accessed 19 November 2020].

Contemporary feminist illness writing can be situated at the intersection of *contemporary feminist life-writing* (Jennifer Cooke) describing formally innovative life-writing published since around 2000 by authors such as Chris Kraus, Claudia Rankine, Virginie Despentes, Sheila Heti, Maggie Nelson and Paul B. Preciado, and *illness writing*, a capacious category which contains writing on the topic of illness.[53] Jennifer Cooke describes 'audacity' as a key aspect and strategy of contemporary feminist life-writing, exemplified in how the authors use bold, experimental forms to 'think from life,' questioning conventional morality and decorum and creating confessional texts focusing on sexuality, trauma, and emancipation.[54] This also holds for contemporary feminist illness writing, in which frankness about bodily (dys)functions and the reality of living with illness accompany bold challenges to ideas of the 'good' patient who always follows their doctor's orders. Fragmentary form, blending of autobiography and critical analysis, and manifesto-like qualities similarly recur in contemporary feminist illness writing.

Contemporary feminist illness writing builds on the political illness writing of the 1970s and '80s, founded in health collectives and the second-wave feminist motto that 'the personal is political'. Texts use personal experiences as a springboard to mount emancipatory anti-capitalist critiques. Like the feminist *Wages for Housework*-campaign, much of contemporary illness writing springs out of a Marxist feminist tradition that analyses gender within a context of unequal capitalist exploitation. Audre Lorde's work, most notably *The Cancer Journals* (1980) and *A Burst of Light* (1988), lay the groundwork for contemporary feminist illness writing both in terms of ideas and genre. In her writing on illness, Lorde blends diary

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[53] Jennifer Cooke, *Contemporary Feminist Life-Writing: The New Audacity* (Cambridge: Cambridge University Press, 2020).

[54] Cooke, p. 3.

extracts, interviews, literary theory, reflective writing, and cultural criticism with an explicit call to arms. She links the experience of illness directly to the influence of capitalist profit-seeking, asking: ‘What would it mean to be living in a place where the pursuit of definition within this crucial part of our lives [i.e., illness] was not circumscribed and fractionalized by the economics of disease in America?’[55]

The UK writer, photographer, and collage-artist Jo Spence’s work has also been foundational and includes many of the features now common in contemporary feminist illness writing. Spence’s work encompasses the visual dimension that recurs in much of this type of writing, combining text with photography, graphic design, video, and digital installations. Additionally, Spence uses constructive and speculative elements that envision an alternative reality. Like many writers and artists after her, Spence sees illness as a microcosm of a wider fight, writing that her work on illness ‘acts as a metaphor for all struggle’.[56] Later examples of this are Ellen Leopold’s *A Darker Ribbon* (1999), Eve Kosofsky Sedgwick’s writing on cancer, and Barbara Ehrenreich’s writing on the cancer industry, such as in the essay ‘Welcome to Cancerland!’ (2001). In these texts, feminist writers place the cultural constructions of illness within wider economical contexts.

Contemporary feminist illness writing is a canon-building project.[57] By establishing a canon of writing through citation, bibliographies, and dialogue with earlier texts, no one writer has to do all of the work by themself. Other frequently invoked ‘ancestors’ range from medieval mystics like Margery Kempe, early writers of illness like Fanny Burney, Alice James, and Virginia Woolf, philosophers like

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[55] Audre Lorde, *A Burst of Light: Essays* (London: Sheba, 1988), p. 99.

[56] Jo Spence, *Putting Myself in the Picture: A Political, Personal and Photographic Autobiography* (London, England: Camden Press, 1986), p. 186.

[57] See Waerea’s project but also Hedva’s ‘Sick Woman Theory’ tumblr blog for examples of how the writers involved construct bibliographies. Johanna Hedva, ‘Bibliography’, *Sick Woman Theory* <https://sickwomantheory.tumblr.com/bibliography> [accessed 30 May 2023].

Simone Weil, and contemporary thinkers like Sylvia Wynter, Judith Butler, and Alison Kafer. As Toni Morrison observed, ‘canon building is empire building,’ and an important part of destroying the hegemony of one empire also lies in building new canons.[58] The building of a canon of ill and disabled writers is a political act that is modelled on and often overlaps with the hugely important continued efforts to build canons of women writers, queer writing, Black writing, and postcolonial writing to mention just a few examples.

The texts I look at often sprawl, situating themselves between genres, forms, and modes, and therefore necessitate several different approaches to analysing them. Although I primarily analyse single-author publications in this thesis, magazines publishing writing by women and non-binary writers living with chronic illness and disability provide a significant foundation that supports the publication of emerging writers. The role of these magazines in continually developing the short-form, inclusive poetics of contemporary feminist illness writing deserves its own dedicated study. Although much can be learned from reading these texts as belonging to the genre of illness memoirs, I have found that opening up the category to include texts and artworks that do not conform to the memoir genre has allowed me to follow arguments and themes across genres and forms and elucidate how the texts build on each other.[59] As I will show, many of the writers reflect deeply on literary form, including and appropriating (work) forms such as the medical case history, the e-

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[58] Toni Morrison, ‘Unspeakable Things Unspoken: The Afro-American Presence in American Literature’, *Michigan Quarterly Review*, 28.1, 1–34 (p. 8).

[59] For studies reading illness narratives in relation to genre, see Frank; Anne Hunsaker Hawkins, *Reconstructing Illness: Studies in Pathography* (West Lafayette: Purdue University Press, 1998); Kathlyn Conway, *Beyond Words: Illness and the Limits of Expression* (Albuquerque: University of New Mexico Press, 2013); Einat Avrahami, *The Invading Body: Reading Illness Autobiographies* (Charlottesville: University of Virginia Press, 2007).

mail, the curriculum vitae, the list, and the accessibility guide. There is a sense that illness challenges the traditional form of the memoir and requires new forms.

While the texts often engage with tropes from illness writing—also called illness narrative (Arthur Frank), pathography, autopathography (Anne Hunsaker Hawkins), or autosomatography (G. Thomas Couser)—they often do so to subvert the tropes. Much of the traditional secondary theory on illness narrative reads it as a means through which the ill person can rebuild an agentive, coherent, narrative self after the crisis posed by illness (e.g., Arthur Kleinman, Arthur Frank). But this 'coherent' self, which classical theorists of the illness narrative see as the final product of writing down and ordering the inherently chaotic experiences of illness, is also an ideally governable neoliberal self as critics including Angela Woods and Sara Wasson have pointed out.[60] In attempting to resist neoliberal constructions of personhood by embracing a more fragmented subject, contemporary feminist illness writing therefore often subverts narrative and formal aspects of traditional illness narratives.

The idealisation of the abstract, rational, autonomous neoliberal subject is not unique to illness narratives, but rather characteristic of the genre of memoir more generally. As Daniel Worden observes, summarizing critiques across the field of life-writing studies by among others Julie Rak, Walter Benn Michaels, and Pamela Thomas, memoir has become 'an easy target for literary critics and cultural studies scholars, who view its vision of self-realization, its dramatization of suffering, and its emphasis on individual self-fashioning as evidence of the genre's privileging of

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[60] Angela Woods, 'The Limits of Narrative: Provocations for the Medical Humanities', *Medical Humanities*, 37.2 (2011), 73–78 <https://doi.org/10.1136/medhum-2011-010045>; Sara Wasson, 'Before Narrative: Episodic Reading and Representations of Chronic Pain', *Medical Humanities*, 44.2 (2018), 106–12 <https://doi.org/10.1136/medhum-2017-011223>.

the entrepreneurial individual'.[61] In other words: memoir is not only *a* but *the* quintessentially neoliberal genre. I suggest that contemporary feminist illness writers react to this common form of the memoir and deliberately undermine it. Using collaborative approaches and writing for and on behalf of a wider movement, contemporary feminist illness writers reject narratives of progress, perfectibility, and the contained subject. They thus present an important alternative to the memoirs of personal growth. Illness writing has always had an important role within life-writing; G. Thomas Couser credits the emergence of the illness and disability narrative with helping to democratise life-writing, turning it from a genre for the rich and famous to something any person could contribute to.[62] As life-writing, particularly in the form of autofiction, continues to be hailed as one of the most innovative subcategories of contemporary literature, it is important to recognise the ways in which illness and disability writers continue to contribute to the genre.[63]

Contemporary feminist illness writing is developed alongside and often inspired by the closely related body of texts pertaining to disability. In *Unruly Bodies: Life Writing by Women with Disabilities* (2007), Susannah B. Mintz describes how disability memoirs have been resisting narratives about overcoming adversity for decades. Mintz looks at how texts by Nancy Mairs, Lucy Grealy, Georgina Kleege, Eli Clare, Connie Panzarino, Anne Finger, Denise Sherer Jacobson, and May Sarton 'challenge the troping of disability in able-bodied culture as deviance, helplessness, insufficiency, and loss'.[64] Chronic illness and disability

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[61] Daniel Worden, *Neoliberal Nonfictions: The Documentary Aesthetic from Joan Didion to Jay-Z* (Charlottesville: University of Virginia Press, 2020), p. 128.
[62] G. Thomas Couser, *Recovering Bodies: Illness, Disability, and Life Writing* (Madison: University of Wisconsin Press, 1997).
[63] Ben Yagoda, *Memoir: A History* (Penguin Publishing Group, 2009), p. 28.
[64] Susannah B. Mintz, *Unruly Bodies: Life Writing by Women with Disabilities* (Chapel Hill: University of North Carolina Press, 2007), p. 1.

often overlap; most chronic illnesses are disabling even if there are many disabilities which cannot be categorised as chronic illnesses. Boyer's chronic heart problems and other impairments after cancer, as described in 'Woman Sitting at the Machine', could be classified as chronic illnesses, resultant disabilities, or aftereffects of the illness. Most of the writers whose texts are analysed in this thesis therefore also identify as disabled. Particularly Chapters 4 and 5, dealing with 'access work' and 'post-work thinking' respectively, use 'disability' as an umbrella term which includes chronic illness. Crip (sometimes *krip*) theory is, in the words of Sami Schalk, 'a strain of disability studies theorizing (inspired by queer theory) that encourages a move away from a primarily identity-based approach to disability and toward a theoretical approach that seeks to trace how disability functions as an ideology, epistemology, and system of oppression in addition to an identity and lived experience'.[65] Mad studies is another subcategory of disability studies with a similarly political intention, focused on mental illness, which contemporary feminist illness writers also often draw on.[66]

In looking at how contemporary feminist illness writing casts light on cultural constructions of (in)capacity, (un)health and (un)productivity, I follow a number of thinkers who have studied supposedly antagonistic concepts in concert. 'To find out what our society means by sanity, perhaps we should investigate what is happening in the field of insanity,' Michel Foucault writes in 'The Subject and Power' (1982).[67] Following Foucault's exhortation, and subsequent work building on this methodology by theorists including Mel Y. Chen on cognition and impairment, and Jasbir K. Puar on capacity and debility, my thesis sees literary

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[65] Sami Schalk, *Black Disability Politics* (Durham: Duke University Press, 2022), p. 8 <https://doi.org/10.1215/9781478027003>.
[66] Aho.
[67] Michel Foucault, 'The Subject and Power', *Critical Inquiry*, 8.4 (1982), 777–95 (p. 780).

explorations of illness as objects that engage with and illuminate contemporary notions of health and productivity. As scholars in disability and Mad studies have shown, the distribution of debility and precarity along lines of race, gender, class, sexuality, and nationality are central aspects of contemporary biopolitics, which is why it is important to study illness as politically situated rather than as a personal tragedy.[68] By looking to resistance and antagonism as sites where the internal rationality of power breaks down and becomes visible, this thesis uses illness activism and the political engagement of literary life writing to challenge contemporary constructions of productivity.

I also build on the field of feminist epistemology to argue that knowledge produced from a marginalised standpoint such as illness (especially as it intersects with gender, race and class in the texts I look at) is a political act to which we must pay attention.[69] Biomedical evidence is not the only truth about illness; as the philosopher Joan Scott has argued, experience is also a form of evidence.[70] Feminist epistemology holds that knowledge produced from the margins is more valuable that knowledge produced from the centre, because it is underrepresented and because those who are excluded from the structures of power can more clearly see them. To summarise, as health and employment are so morally and ideologically invested, I maintain that we need to pay extra attention to thinking from positions of unhealth and unemployment.

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[68] See e.g. Liat Ben-Moshe, *Decarcerating Disability: Deinstitutionalization and Prison Abolition* (Minneapolis: Univ Of Minnesota Press, 2020); Nirmala Erevelles, ‘Crippin’ Jim Crow: Disability, Dis-Location, and the School-to- Prison Pipeline’, in *Disability Incarcerated*, ed. by Liat Ben-Moshe, Chris Chapman, and Alison C. Carey (New York: Palgrave Macmillan, 2014), pp. 81–100; Jasbir K. Puar, *The Right to Maim: Debility, Capacity, Disability* (Durham: Duke University Press Books, 2017); Shelley Lynn Tremain, *Foucault and Feminist Philosophy of Disability* (Ann Arbor: University of Michigan Press, 2017).

[69] Lorraine Code, ‘Feminist Epistemology and the Politics of Knowledge: Questions of Marginality’, in *The SAGE Handbook of Feminist Theory*, ed. by Mary Evans and others (Thousand Oaks: SAGE, 2014), pp. 9–25.

[70] Joan W. Scott, ‘The Evidence of Experience’, *Critical Inquiry*, 17.4 (1991), 773–97.

A guide to the structure

Each chapter focuses on a type of work/labour which contemporary feminist illness writers describe as entailed by, interlinked with, or afforded by chronic illness. I look at how the type of work/labour is explored in the texts and the literary forms through which it is represented. The thesis looks at creative work, administrative/management labour, investigative/diagnostic labour, access labour, and finally the more abstract 'work of dreaming' alternate futures.[71]

Chapter 1 explores how the creative work of writing is shaped by illness. I focus on passages in which the process of writing is described reflexively and metatextually. I suggest that this foregrounding of *process* prompts new critical models of illness texts and their objectives. The most influential critics of the 1990s and early 2000s often describe illness writing as a therapeutical process; narratives born from powerful innate impulses (Hunsaker Hawkins), consisting of stories told through bodies who need to *testify* to their experiences (Frank). These formulations elide the deliberate effort involved in writing and describing it instead as part of a natural process of healing. In many contemporary texts about chronic illness, insistence that the texts are outcomes of deliberate and skilled creative *work* goes hand in hand with a rejection of the therapeutical and the notion of 'healing'. Writers reject the notion that they need to 'overcome' their illness or 'gain something' from it. I argue that instead of the plot of the individual journey through illness, they

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[71] The type of labour which is conspicuously absent in this list is care labour/care work. I touch on care labour/work several times in the thesis where relevant but omit a theorisation of it for reason of scope. See e.g., Arlie Hochschild, *The Second Shift: Working Families and the Revolution at Home* (New York: Penguin Books, 2012); Nancy Folbre, *Who Cares? A Feminist Critique of the Care Economy* (New York: Rosa Luxemburg Stiftung, 2014); Amelia DeFalco, *Imagining Care: Responsibility, Dependency, and Canadian Literature* (University of Toronto Press, 2016); The Care Collective and others, *The Care Manifesto: The Politics of Interdependence: The Politics of Compassion* (London: Verso Books, 2020).

develop non-teleological forms which can tell collective and structural stories, and better represent the ongoing, cyclical, and shared experience of chronic illness.

Chapter 2 explores the ubiquitous discourse of chronic illness as work. I examine different related metaphors: illness as a full-time job, the illness 'career,' the ill person as an enterprise, and the sick woman as a precarious worker. I contrast these to the metaphor for illness which has received the most critical attention: illness as battle or war. I argue that the metaphors of illness as work each have different implications and serve different purposes. However, analysed together, the discourse achieves several things. Firstly, it reflects the contemporary 'active sick role,' characterised by the pervasiveness of 'patient work', the administrative and management labour required by those who are ill. Secondly, the metaphors allow those who are chronically ill to claim admittance to a framework of value from which they are often excluded: the neoliberal worker-citizen. Thirdly, the metaphors facilitate the rendering of the ill subject as a political agent. Finally, I argue that the metaphor of the chronically ill person as a precarious worker is particularly important. It allows writers to visualise certain affective dimensions of illness, including the sense of development as foreclosed, as well as to join a broad alliance of those who suffer under contemporary capitalist norms. The figurative language provides access to a history, a register, and a set of forms related to labour struggle including the acts of unionising, going on strike, withdrawing labour, and negotiating with those in power, which the texts seize.

Chapter 3 moves from figurative claims of the ill person as a worker to the more concrete: how the labour entailed by illness is represented in the texts. I focus particularly on texts describing the experience of living with invisible, contested, or poorly understood illnesses. These texts demonstrate that the labour entailed by illness exceeds what is encompassed by the concept of ‘patient work’ as it is undertaken prior to being given a diagnosis or by people who are not even recognised as ‘patients’. Much labour is also undertaken outside the boundaries of the healthcare system, in private lives, online communities, and with alternative providers. I describe this as reproductive illness labour or investigative labour. In the texts, a particular form is often used to represent this investigative and management labour: the list. The types of lists used by contemporary illness writers are often drawn from specific domains such as the medical (symptom lists, medical case histories), digital media (the listicle), and moral accountancy (list of virtuous acts and transgressions) and mediate particularly fraught dimensions of the contemporary illness experience. These are often related to rendering the subject as ‘legible’ in medical and social contexts. I look at the list as an example of a non-teleological form, arguing that writers use it to eschew causal narratives and instead express how strain builds over time.

Chapter 4 looks at ‘access work,’ the labour undertaken to expand disability and illness accessibility in relation to events, publications, organisational work, and residencies. In contrast to ‘patient work’ and other reproductive and investigative illness labour which is undertaken on behalf of the ill person themselves, ‘access work’ has more expansive ambitions. It describes how those who are ill use the legal protections they have in the workplace to ‘reasonable’ accommodations or adjustment to enact changes in workflows and work practices. These engagements with bureaucracy as a site of the negotiation of the ‘reasonable,’ and ‘normal’ also occur in texts by contemporary feminist illness writers, not least in the use of forms like the e-mail and emerging textual genres such as the accessibility ‘rider’ and the ‘accessibility guide’. This chapter looks at the changed status of contemporary feminist illness writing; after having gained recognition, writers must reckon with a new (albeit still precarious) position within the mainstream and how to use the (still relatively modest) power this position affords them. I argue that access work becomes a framework for expressing the revised objectives of illness writing, combining literary and activist praxis.

Finally, Chapter 5 looks at the 'work of dreaming'; of envisioning alternative societies and futures in which illness is not oppressed. I propose that illness writing has a long history of being used as a form of economic, post-work thinking. Going back to Alice James' diaries and Virginia Woolf's 'On Being Ill' (1926), I argue that these works engage with contemporaneous discussions of the societal role of labour and leisure. I argue that Woolf's text is not simply a meditation on illness but part of a conversation by Marxists as well as economists such as Bertrand Russell and John Maynard Keynes about the future of work and the understanding of meaningful activity outside a framework of work. Analysing the engagement between illness writing and anti-/post-work theory, I argue that it is important to pay heed to this intertwined history. Illness has often been seen as a problem for utopian thinking, an issue to be solved or eradicated. However, contemporary writers build on previous texts to explore how the knowledge possessed by ill bodyminds (e.g., conserving energy and dealing with limited resources) could lead the way to better, more sustainable societal models. The final chapter thus returns to the site of Chapter 1, the sick bed, but posits it as a space of utopian thinking and leisure rather than work as we currently understand it. I contend that thinking alternatives to the 'good' labouring body is a crucial contribution of illness writing.

Chapter 1: Working Through Illness: Narrative, Positionality, and the Work of Writing

In an essay about the Protestant work ethic and the difficulty of living with chronic pain in a society which values productivity above everything else, Sonya Huber suddenly switches to the present tense:

> today has been another day of weather change, and my joints jar against the shifts of barometric pressure. It is a clogged, gray-sky, swollen-finger day. I am flat on my back and wrapped in the electric blanket, which twists around me and encases me. I am typing with the iPad almost vertical, held aloft on my knees, trying to press the letters while torquing my wrists as little as possible.[1]

The passage breaks away from the coolly narrated argumentation of the rest of the essay, its academic style underpinned by engagement with critical literature by Arthur Frank and Kathi Weeks on the concepts of work and illness. In a move something like breaking the fourth wall, or perhaps a Shakespearean aside, Huber addresses the reader directly from the situation of writing. She moves from an overview of a complicated theoretical relationship between work and illness to the specific: describing the moment of creative labour and how it is shaped by living with rheumatoid arthritis. This literary device is a reminder that the text comes from somewhere; that it was produced, laboriously, from a particular orientation (flat on her back) and by a bodymind with its particular (dis)abilities and sensations.

The passage subverts traditional images of the author upright at their desk. As the philosopher Adriana Cavarero describes, the physical position of being upright is invested with ideological values such as masculinity, morality, and

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[1] Huber, p. 49.

rationality.[2] To be *inclined*, instead, Cavarero argues, is to inhabit a feminised, embodied subject position 'marked by exposure, vulnerability, and dependence'.[3] Working 'inclined' from a bed or a sofa is of course not unique to illness by any means, even if it is, in the words of Leah Lakshmi Piepzna-Samarasinha, 'a time-honored crip creative practice'.[4] Preferences, the wish for variety, the lack of space to have a table, or being suddenly barred from going to the office as during the Covid-19 pandemic, can all be reasons for working 'inclined'. But in the passage, Huber describes how the horizontal position is part of what it means for her specifically to write with rheumatoid arthritis in that moment. She does not present the position as inferior to the image of the 'upright' (in both senses) author; it is merely different, shaped by her illness and the particularity of her bodymind and environment. Huber thus engages the social model of disability, and anchors her text in a particular embodiment and positionality.

The writing position Huber describes is marked by several different kinds of dependence. Huber describes how the weather impacts her body, with the high air pressure worsening her symptoms. On the other hand, the surface she rests on, the electric blanket that warms her, and the iPad she types on all support her, making it possible for her to write during her flare-up. The agency of these objects is emphasised by the way Huber makes them grammatical subjects. 'Today', 'my joints', and 'the electric blanket' are all made actors, nodes in a network that shapes the situation of writing.[5] The passage describes the chronically ill writer as

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[2] Adriana Cavarero, *Inclinations: A Critique of Rectitude*, trans. by Adam Sitze and Amanda Minervini (Stanford, CA: Stanford University Press, 2016), p. 6.

[3] Cavarero, p. 11.

[4] Leah Lakshmi Piepzna-Samarasinha, *Care Work: Dreaming Disability Justice* (Arsenal Pulp Press, 2018), p. 17.

[5] See actor-network theory, developed by Bruno Latour and others. See Bruno Latour, *Reassembling the Social: An Introduction to Actor-Network-Theory* (Oxford: Oxford University Press, 2007).

fundamentally contingent, connected, and embedded, a kind of ‘cyborg’ in Donna Haraway’s conception of the term, a reference explicitly made elsewhere in Huber’s essay collection.[6]

Huber’s essay is just one example of how contemporary feminist illness writers visualise the creative labour of writing and the specific situation of writing while ill. Passages like the above, in which writers break away from a more detached description or narrative style to focus on the embodied experience of writing, are a common stylistic device in contemporary feminist illness writing, occurring in texts by Porochista Khakpour and Alice Hattrick among others.[7] The metatextual commentary draws attention to the text as a fabricated object and the result of strained, embodied labour. In this chapter, I look at a number of these passages, which are sometimes marked off from the surrounding text by brackets.

I argue that the embodied descriptions of the act of writing while ill exemplify how contemporary feminist illness writers deliberately foreground *process*. The attention to the process of writing, rather than the effects and outcomes of *having written*, indicates a shift away from earlier illness texts and how these have been read. Arthur Frank, who has written the most influential taxonomy of narrative models of illness writing, *The Wounded Storyteller* (1995), idealises the story pattern he calls the ‘quest narrative’.[8] This is a narrative of overcoming, in which the ordering of chaotic experiences into a narrative plot of transformation helps ill writers take narrative control over their experiences and thus heal (literally or figuratively). Throughout this thesis, I will return to the ways in which contemporary ill writers refuse this narrative model. Huber, in her essay, writes that she refuses to

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[6] Huber, p. 34.
[7] Khakpour, p. 251; Alice Hattrick, *Ill Feelings* (London: Fitzcarraldo Editions, 2021), p. 48.
[8] Frank, pp. 75; 115.

‘f[i]nd lessons to extract’ from her chronic illness.[9] Writers including Huber argue, alongside a newer wave of critics, that the idealisation of continuous personal growth is part of neoliberal ideology. Moreover, narrative teleology does not reflect the reality of living with chronic illness, in which remission is typically only temporary, followed by the eventual relapse. Ill writers insist on the right to not ‘overcome’ their illness, learn lessons from it, or be inspirational. They want to simply be as they are, and for their experiences of pain, anger, and frustration to be represented without having to be framed as means to a process of personal healing. As the group *Recovery in the Bin* puts it, rejecting the concept of ‘recovery’, ‘doesn’t mean we want to stay ‘unwell’ or ‘ill’ (whatever that means), but that we reject this new neoliberal intrusion on the word ‘recovery’ that has been redefined, and taken over by marketisation, language, techniques and outcomes’.[10]

The first section of this chapter looks at how contemporary illness writers foreground process and how this connects to a preoccupation with the concept of work. I contrast different ways in which the processing of the experiences of illness have been presented, arguing that contemporary writers break with the intention to ‘process’ their experiences as described in three canonical texts in the medical humanities which theorise the idea of narrative as a healing force: Anne Hunsaker Hawkins’ *Reconstructing Illness* (1993), Frank’s *The Wounded Storyteller*, and Rita Charon’s *Narrative Medicine* (2008). In the second section, I look at recent critiques of the idealisation of ‘narrative’ in critical analysis of illness writing. Building on the contributions of a new generation of medical humanities scholars who de-centre concepts of teleology in their analysis of illness writing, I read the moments of

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[9] Huber, p. 46.

[10] Recovery in the Bin, ‘About’, *Recovery in the Bin* <https://recoveryinthebin.org/> [accessed 23 May 2023].

reflexive present-tense attention to the situation of writing as part of a rejection of the ideological invested telling of an illness story as a way of healing. However, I also explain my own choice of terminology; rather than calling these approaches non-narrative, I instead describe them as non-teleological. In the third section, I return to the foundational texts by Hawkins, Frank, and Charon to analyse in more detail how contemporary writers break with these. I argue that going away from descriptions of a 'communicative body' (Frank) towards thinking about a writer undertaking the creative work of writing about illness indicates a shift from a seemingly natural, spontaneous process to one that is effortful, deliberate, and skilled.[11] I propose 'work' as a useful theoretical concept in that it foregrounds the effortful activity elided by ideals of the 'communicating body' and the healing act of storytelling. In the fourth section, I explore how these moments of metatextual description of the work involved in writing while ill are part of the texts' feminist methodology. I argue that they line up with the long-standing feminist practice of making visible previously 'invisible' labour and precisely situating the production of knowledge. Feminist epistemology requires that knowledge is produced from an embodied and situated necessarily *partial* perspective.[12] I read the commonly occurring metatextual descriptions of the embodied work of writing in contemporary feminist illness writing as disclosures of such partial perspectives.

This chapter thus lays the groundwork for the rest of the thesis in starting to unpack 1) how contemporary feminist illness writers differ from earlier generations of illness writing, 2) which new critical questions are prompted by these new

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[11] Frank, p. 48.

[12] Donna Haraway, 'Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective', *Feminist Studies*, 14.3 (1988), 575–99; Adrienne Rich, 'Notes toward a Politics of Location', in *Blood, Bread, and Poetry: Selected Prose 1979-1985* (New York, NY: W. W. Norton & Company, 1994), pp. 210–31.

dimensions and preoccupations in the texts, and 3) what the concept of 'work' can contribute to readings of contemporary illness writing. I emphasise the importance of drawing on feminist and anti-capitalist bodies of thought in order to be attentive to the ideological and political ramification of contemporary feminist illness writers' foregrounding of process. I propose that work—as a theme, a lens through which to look at process, and a way of reading—can illuminate aspects of contemporary illness writing that a method that idealises teleological narratives cannot.

Two ways of working through illness

Huber's description of typing flat on her back, with her iPad held vertically on her knees, is documentation of how her illness shapes her practice as a writer. In the essay, Huber describes how she writes at least partially because she *has* to: it is part of her job as an academic and a writer, work that can be pleasurable at times but that is also necessary because it provides her with access to an income and the healthcare she needs to live. 'I continue working because I must. I continue writing because I need to,' Huber observes.[13] Her chosen career provides her with the flexibility she needs to accommodate her illness and work through it, in the sense of producing continuously at the rate she needs to in order to keep the job. The passage thus describes the reality of working through and around a chronic illness which flares and abates, and the technology she engages with to do so.

This is a reality which is documented in almost all illness texts, especially those produced in the US, where employment is a prerequisite for healthcare, earning time off, and qualifying for disability benefits. In the US, having a serious chronic health condition only decreases employment probability by 3 per cent and

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[13] Huber, p. 49.

having 2-3 serious chronic health conditions decreases it by 11 per cent—and the chronically ill people in employment work as many hours as those without a chronic health condition.[14] In the US, the contemporary experience of chronic illness is thus defined by the need to keep up work no matter the seriousness or intrusiveness of symptoms. As Anne Boyer writes in *The Undying*: 'Whether I am dying or not, I still have bills to pay, a child to support, students to teach, a job to keep: I have to go to work'.[15]

This mundane sense of *working through illness* contrasts markedly with the therapeutic sense of the phrase, deriving from Sigmund Freud's work on psychoanalysis. Freud uses *working through* for the patient's labour in psychoanalysis of recognising resistances and overcoming them.[16] In psychoanalysis and trauma studies, *working-through* is often contrasted with *acting-out* as the dominant modes of reacting to trauma. The psychoanalyst Dominick LaCapra describes *acting-out* as characterised by 'compulsive repetition', 'a tendency to relive the past, to exist in the present as if they were still fully in the past, with no distance from it'.[17] *Working-through*, on the other hand, means 'gain[ing] critical distance on a problem, to be able to distinguish between past, present and future' and consequently means that the person 'acquires the possibility of being an ethical agent'.[18]

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[14] Ward. The study only included the 10 most common chronic health conditions in the US: hypertension, coronary heart disease, stroke, diabetes, cancer, arthritis, hepatitis, weak/failing kidneys, current asthma, and chronic obstructive pulmonary disease.

[15] Anne Boyer, *The Undying* (London: Allen Lane, 2019), p. 275.

[16] Sigmund Freud, 'Remembering, Repeating and Working-Through (1914)', in *The Standard Edition of the Complete Psychological Works of Sigmund Freud*, trans. by Joan Riviere (London: Hogarth Press, 1950), XII, 145–57 (p. 155).

[17] Dominick LaCapra, '"Acting-Out" And "Working-Through" Trauma', *Shoah Resource Centre*, 9 June 1998, p. 2 <https://www.yadvashem.org/odot_pdf/microsoft%20word%20-%203646.pdf> [accessed 4 June 2023].

[18] LaCapra, pp. 2–3.

This distinction is significant here because it is echoed in the foundational scholarship on illness writing. Anne Hunsaker Hawkins' *Reconstructing Illness* (1993) and Arthur Frank's *The Wounded Storyteller* (1995) both draw on trauma theory and related theorisations of artistic works as testimony in the late 1980s and early 1990s. Both texts understand serious illness as a form of trauma, in the sense of 'a *belated* response to an overwhelming event too shattering to be processed as it occurs'.[19] As Hawkins puts it, serious illness is 'a kind of experience that is so painful, destructive, and disorienting' that it causes psychic injury.[20] Although the disorientation of serious illness could prompt the patient to be *acting-out*, Hawkins situates the act of writing about illness as a form of *working-through*. The injury prompts a natural 'counterimpulse toward creation and order'; an instinctive human process of reparation which involves narrative expression.[21] Illness writing is a result of this 'counterimpulse'; its purpose 'is not only to describe this disordering process but also to restore to reality its lost coherence and to discover, or create, a meaning that can bind it together again'.[22] While serious illness causes psychic injury, the act of writing about it can thus heal this wound. This places illness writing (verb) as a therapeutic process and illness writing (noun) as the result and documentation of this process.

Like Hawkins, Frank argues that 'stories can heal' the attendant psychological injuries that medical treatment does not address and that patients 'need to become storytellers in order to recover the voices that illness and its treatment often take away'.[23] Frank distinguishes between different ways in which patients tell

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[19] Lucy Bond and Stef Craps, *Trauma*, The New Critical Idiom (London; New York: Routledge, 2019), p. 3.
[20] Hawkins, p. 24.
[21] Hawkins, p. 24.
[22] Hawkins, p. 3.
[23] Frank, p. xiii.

stories, with the 'chaos narrative' closely resembling a situation of *acting-out*. A 'chaos narrative', Frank writes, is 'an anti-narrative of time without sequence, telling without mediation, and speaking about oneself without being fully able to reflect on oneself'.[24] He contrasts the chaos narrative with more constructive narrative models, the ideal of which is the 'quest narrative'. Freud's language of resistance, and the importance of persisting through it, is echoed in Frank's description. The teller of the quest narrative follows this process:

> First they resist the call: the disease, or trauma, or chronic pain that is being forced upon their bodies. As their stories develop and as they develop in their stories, they resist the silence that suffering forces upon their bodyselves. Finally their resistance finds a voice; they make suffering useful. In the wounds of their resistances, they gain a power: to tell, and even to heal.[25]

In telling their stories through quest narratives, patients come to 'accept illness and seek to *use* it'.[26] In finding lessons and 'something to be gained' from the experience, they re-gain a sense of autonomy; the quest narrative creates 'its own time out of interrupted time, or its own coherence out of incoherence'.[27] Similarly to LaCapra, Frank argues that this is an ethical narrative practice; the storyteller becomes a 'communicative' or 'dyadic' body through the telling of their story.[28]

Neither Hawkins nor Frank reference the Freudian conception of *working-through*, but their descriptions of illness writing come very close. Through facing resistance and chaos, and overcoming a sense of incoherence, the ill storyteller—when telling a constructive story in which something is gained from illness—regains a critical distance, moving from existing in an on-going present to being able to

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[24] Frank, p. 98.
[25] Frank, p. 182.
[26] Frank, p. 115.
[27] Frank, pp. 115; 165.
[28] Frank, pp. 37–40.

distinguish between past, present, and future. This understanding of *why* illness writing exists, and the outcomes, for the writer, in writing down a story about learning certain lessons, has been very influential in the medical humanities, and continues to dominate. (As I will describe in the next section, however, this is changing.)

Hawkins' book, as the first long study on book-length accounts of illness, and Frank's text, arguably the most influential study of illness writing to date, have a large role in founding the critical field of analysing illness writing, and continue to be touchstones for medical humanities scholars. The similarity to the Freudian concepts illuminates certain assumptions in their readings of illness writing. Although the undertaking of labour is not named as such in Frank's and Hawkins' critical texts, we might still recognise an implication that the right kind of hard work is both necessary and inherently morally improving. Although the point should not be overstressed, Eli Zaretsky points to the natural affinities between these aspects of Freud's psychoanalytical practice, especially as it was adopted by Post-war American practitioners, and the Protestant work ethic.[29]

While these texts have brought important attention to illness writing and helped found the field, describing the telling of stories of healing and overcoming as a natural, instinctive, and 'healthy' response to illness has contributed to eliding the effort that is involved in writing. The representation of illness writing as arising from a natural impulse has significant implications for how the writing is conceptualised and literary craft presented. This can be seen in the verbs Frank uses throughout *The Wounded Storyteller*. By describing 'the body' as *communicating*, *telling*, *testifying*, and *turning* experiences into story, the process of writing is erased. The same is the

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[29] Eli Zaretsky, *Political Freud: A History* (Columbia University Press, 2015).

case for Hawkins' terminology of illness writing as 'impulse'. Unni Wikan has the formulation that perhaps most clearly underlines the biological dimension seen at play in the telling of illness stories, that people 'bleed stories'.[30] The choice of 'story', rather than 'words' or 'text', emphasises that these critics are particularly interested in the plots of illness texts.

Of course, these formulations of spontaneous creation are often borrowed from the authors. Hilary Mantel, for example, describes how in the hospital following an operation, she writes incessantly, and how this writing works therapeutically to restore a sense of agency for her. 'The black ink, looping across the page,' she writes, 'flowing easily and more like water than like blood, reassured me that I was alive and could act in the world'.[31] In the same text, however, she also includes the following passage:

> Just before my discharge I scribbled, 'When I go home I could write up my hospital diary. Or, you know, I could not. I could defiantly leave it unprocessed, and that way the marks of experience might fade.'[32]

By quoting what she 'scribbled' in hospital, the narrator clearly demarcates that type of writing from the rest of the text. The narrator presents her writing as words or text; the act of 'scribbling', however, suggests a lack of seriousness and rigour. It is not described as labour, but the emphasis on the ink being more like water than blood underlines that she has not bled a 'story' either—and the passage documents her deliberation to keep it that way. The passage presents re-writing and editing the text as acts which will solidify the experience, imprinting the 'marks of experience'

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[30] Unni Wikan, 'With Life in One's Lap: The Story of an Eye/I', in *Narrative and the Cultural Construction of Illness and Healing*, ed. by Cheryl Mattingly and Linda C. Garro (Berkeley and Los Angeles: University of California Press, 2001), pp. 212–36 (p. 217).

[31] Hilary Mantel, *Ink in the Blood: A Hospital Diary* (London: Fourth Estate, 2010), no pagination.

[32] Mantel.

further on her body. More processing of the text is thus not presented as a positive or ethical practice—rather, the narrator implies taking delight in considering refusing to do so. As the text only sparsely cites the actual hospital diary, she must have done some 'processing'. However, the last two sentences of the passage make the point that although she has indeed written up the diary, she has refused the act of imposing plot or genre on the text. She writes that she has kept the text open, able to be 'a shaggy dog story, or a mangled joke with the punchline delivered first' or something else entirely, citing the reason of chronicity necessitating a literary form that similarly refuses finality.[33]

Many writers publishing after Mantel similarly refuse the *working-through* of illness and the telling of quest narratives. I see the metatextual, present-tense descriptions of writing as closely linked to this. In the 'Acknowledgments' to Porochista Khakpour's memoir *Sick* (2018), Khakpour demonstrates how she privileges process over outcomes in her depiction of illness writing. Khakpour breaks away from thanking those who supported her during the writing and publication of the book to describe the difficulty of writing it. She allows the writing process to be clear on the page:

> Part of the difficulty in writing *Sick* was that I was quite sick during the making of it, and continue to be. (As I input final edits now, I am doing them between a lengthy hospital visit; even when the ink was barely dry, my failing body kept trying to rewrite this, to make sure it never ended.) You are reading the middle of the story, I suspect, but I'm not sure where or when it will all end, so one might as well tell it now.[34]

The description of how her 'failing body kept trying to rewrite this, to make sure it never ended' documents a desire to stay in the process. Her reason for doing so is not

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[33] Mantel.

[34] Khakpour, p. 251.

to shape her text into a clearer story; in fact, she writes that the text only has the status of a 'middle', lacking a beginning and an ending. Rewriting, for Khakpour, is not a way of imprinting her experiences more deeply on her body. Instead, the in-process text seems to be the only form that can accurately contain her experience of chronic illness; any imposed finality seems to remove the words from her lived experience.

The acknowledgements section is often where a 'behind the scenes' view of the book is provided: where it was written, who was involved or supported the process, and whose work inspired it. Khakpour emphasises her own process and embodiment in the process. The situation of writing—here, editing—is not as precisely described as in Huber's essay, but nonetheless retains immediacy by inscribing itself in a particular moment of the text's production. The parenthesis marks a break in the text and a switch to the present tense. Moreover, Khakpour writes that she is inputting final edits 'between a lengthy hospital visit,' a phrase that does not make grammatical sense, but supports a sense that the passage was added in that final round of editing, escaping its scrutiny. Retaining this unpolished sentence also reinforces the point she is making in the passage about never finishing the process of illness, or the writing about it, implying that this refusal of an 'after-the-fact' narrative position is a necessity for writing accurately about chronic illness.

This is similar to how Huber, in her essay, writes that she refuses to 'f[i]nd lessons to extract' from her chronic illness.[35] Illness has changed her fundamentally, she writes, but she resists the impetus to find a positive lesson in the pain; change does not have to mean development or progression.[36] Similarly, by refusing critical

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[35] Huber, p. 46.

[36] Huber, p. 46.

distance and writing in the present tense, Khakpour's narrator refuses the *working-through* of her illness in the sense of processing and resolving her experiences. She documents both her initial expectation that she would tell a story about recovery and the narrative consequences when she realised this was not possible in the conclusion to the main body of the text. 'The story didn't end as I imagined so many times: in the end I would make it,' she writes.[37] She has not *made it* in the sense of becoming healthy, and neither does she want to assure the reader that she has arrived in a better place—neither physically nor mentally or emotionally. Instead, she insists on her right to be angry about her illness and unresolved in her relationship to it. She emphasises this by comparing two different texts. The first is the imaginary 'The Book I Sold', which is

> a story of triumph, of how a woman dove into the depths of addiction and illness and got well. She got herself better. She made it. The Book I Sold might even imply you can do it too. Or anyone can.[38]

'The Book I Sold' is a traditional illness memoir of overcoming and *working-through*: a 'quest narrative'. She explicitly describes this story as espousing and perpetuating a work ethic that holds that illness can be cured with hard work and persistence. But she cannot use this narrative structure because it is not true to her story. Instead, she writes *Sick*, a text without 'full circles', 'pretty arcs', and 'character development'.[39] This is a book that serves as a reminder, she writes, 'that illness will always be with you as long as life is with you. And tragedy will be with you too'.[40] It is told in the 'depths' of illness rather than on the other side of them.

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[37] Khakpour, p. 250.
[38] Khakpour, p. 245.
[39] Khakpour, p. 245.
[40] Khakpour, p. 245.

Huber and Khakpour refuse to make their texts 'quest narratives' and thus move away from Frank's conception of what an ethical practice of ill storytelling is. (I will go into the alternative ways in which these and other writers conceive of their writing as ethical in Chapters 4 and 5.) The use of the present tense is particularly significant, as it exemplifies the move away from the critical distance described in Freud and through to Frank and critics working in his tradition. The therapeutic way of reading illness writing links narrative tense to literary form, as exemplified in the writing of Ruth Nadelhaft. Nadelhaft describes how illness

> takes place in what seems an eternal present. Past health and future recovery vanish in the face of the endless formlessness and present tense of the experience of pain […]. Literature offers form, structure, and the illusion of dimension to what was out of control and without limit.[41]

While illness is a fundamentally chaotic and 'formless' experience, 'literature' offers the opposite: coherent form and familiar plot lines. While she concedes that control will always to some degree be an 'illusion,' 'literature' and its 'form' and 'structure', she argues, can nonetheless function as a framework for making sense of difficult experiences. Writing about illness is a way of regaining agency and control; 'narrative' offers shape and structure and allows the writer to move on from the 'eternal present'. Kathryn A. Jacobi, likewise, uses the work of Arthur Kleinman to read the 'literary types and structures' in illness memoirs in order to 'understand how the writing helps the writers [...] gain back some lost sense of self caused by the illness they suffered or are suffering through'.[42]

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[41] Ruth Nadelhaft, 'The Experience of Illness', in *Imagine What It's Like*, ed. by Ruth Nadelhaft (Honolulu: University of Hawai'i Press, 2008), pp. 3–5.

[42] Kathryn A. Jacobi, 'Embodied Consciousness in Non-Fiction Illness Narratives : A Phenomenological-Sociological Approach.' (University of Louisville, 2011), p. 20. <https://pdfs.semanticscholar.org/2d0f/40f3ec0f9548a7b7874cf0e569eb4ae2fa57.pdf?_ga=2.133416206.1445668032.1568656482-1220885878.1568656482> [accessed 16 September 2019].

Although parts of their illness texts are written with the critical distance idealised by theorists like Frank and Nadelhaft, the narrative intrusions of the present tense in Khakpour and Huber insist on representing the ‘endless formlessness and present tense’ of chronic illness. Their use of the present tense marks a stark departure from traditional accounts of what an illness text does and why they are written, and the affinities of these stories with neoliberal growth narratives. The writers foreground the ways in which they work through illness in the sense of working *while* ill, using detailed scenes and descriptions, while refusing to ‘resolve’ or overcome their experiences of illness. Description of working through illness replaces the act of *working-through* their experiences.

What is made clear by the different passages I have analysed in the chapter—creative and critical—is how much is at stake in concepts like ‘story’, ‘narrative’, ‘structure’, ‘literature’, and ‘form’. When Nadelhaft writes that ‘literature offers form, structure, and the illusion of dimension’ she is certainly not referring to modernist or post-modernist approaches characterised by fragmentation, generic multiplicity, or destabilizing of meaning. The next section will look at what exactly *is* implied by how Hawkins, Nadelhaft, and Frank use these terms, and contrast this with the emergence of recent ‘non-narrative’ approaches to illness writing.

Critiques: non-teleological narrative structures

The contemporary feminist illness writers analysed in this thesis all to some degree resist the idea that the purpose of illness writing is to grow and learn. Part of this is resistance to the idea that illness writing is a task undertaken primarily for personal reasons. The writers are often more interested in the activist purposes of the texts and how they participate in wider anti-ableist, feminist, and anti-capitalist movements.

They avoid describing writing as therapeutic, preferring instead to describe it as difficult. The therapeutical reading—that telling teleological stories about illness is a natural and healthy impulse of healing—is closely related to the conception of 'narrative' as innately 'ordering' as described above. Before going on to examine alternative narrative models, I want to look at how this understanding of illness writing came to dominate the medical humanities. For the purposes of this thesis' focus on the concept of work, I also elaborate on the historical relationship between the workplace and the development of 'trauma' as a concept and how this connects to the foundational critical readings of illness writing.

Hawkins and Frank constructed their foundational theories of illness writing at a specific moment in trauma theory, in the early 1990s when trauma was beginning to become a mainstream concept. The Western understanding of trauma as a psychological injury, however, goes back to the middle of the nineteenth century and is closely tied to discussions of accountability and compensation for workplace injuries, first in relation to railway workers and later in relation to injured soldiers.[43] In 1980, post-traumatic stress disorder (PTSD) was included as a diagnosis in the *DSM-III* after a long campaign on behalf of veterans of the Vietnam war.[44] In the following years feminist psychiatrists such as Judith Herman intensified their efforts to have the diagnosis broadened so as also to be seen as stemming from repeated, prolonged abuse such as in childhood or domestic violence. This helped secure the rights of women and children to gain access to treatments which were until then

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[43] *Traumatic Pasts: History, Psychiatry, and Trauma in the Modern Age, 1870–1930*, ed. by Mark S. Micale and Paul Lerner, Cambridge Studies in the History of Medicine (Cambridge: Cambridge University Press, 2001) <https://doi.org/10.1017/CBO9780511529252>; Roger Luckhurst, *The Trauma Question*, 1st edition (London ; New York: Routledge, 2008).

[44] Allan Young, *The Harmony of Illusions: Inventing Post-Traumatic Stress Disorder* (Princeton, NJ: Princeton University Press, 1997), p. 108.

primarily offered to veterans.[45] For over a century, trauma was thus primarily understood as related to work-adjacent or workplace injuries (soldiers being one type of worker) before it was also applied to results of violence in interpersonal relationships.

As the concept of trauma gained recognition, scholars from a wide range of disciplines started exploring applications to their fields, including to the early medical humanities. Like many others, Hawkins was inspired by the Pulitzer Prize-winning work of the psychiatrist and pacifist activist Robert Jay Lifton, whose studies of survivors of the Hiroshima nuclear bombing (*Death in Life*, 1967) and Vietnam War veterans (*Home from the War*, 1973) contributed to the creation of PTSD as a diagnosis and the development of new treatment protocols. In *Reconstructing Illness*, Hawkins builds on Lifton's concept of 'formulation' as a process of restoring a sense of agentive self and a connection to others.[46] Hawkins sees illness writing (and publishing) as either a 'parallel process' or 'the final stage' of psychic rebuilding after incurring trauma.[47] She thus compares the effects of experiencing serious illness and war and sees the healing from both as following a common process.

Frank, who published *The Wounded Storyteller* a year later, also acknowledges his intellectual debt to trauma studies, specifically studies and works related to the Holocaust, which had become the focus of literary scholarship on trauma at the time. Often starting from Theodor Adorno's claim that 'to write poetry after Auschwitz is barbaric', literary scholars were discussing the role of literature in representing what was seen as the fundamentally uncommunicable experience of

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[45] Bond and Craps, p. 40.
[46] Hawkins, p. 25.
[47] Hawkins, p. 25.

trauma.[48] Frank describes how Holocaust narratives helped him understand his own experience of illness.[49] Moreover, he adopts an ethical language of testimony and witnessing based on the work of Holocaust scholars including Lawrence Langer, Primo Levi, Shoshana Felman, and Emmanuel Levinas. Frank even describes how he considered including Holocaust narratives in *The Wounded Storyteller*, something he eventually decided against for reasons of wanting to distinguish between suffering that 'has its cry attended to [like illness], and suffering that is left in its own uselessness [like the Holocaust]'.[50] However, although Frank cites the leading Holocaust scholars as influences, his methodological approach is closer to Hawkins' work building on the therapeutic intention of Lifton in focusing on the potentially healing power of narrative. Scholars working on the Holocaust often emphasised the ongoing consequences of trauma rather than their resolution. As Cathy Caruth writes, 'far from telling of … the escape from a death', stories of trauma 'rather attests to its endless impact on a life'.[51]

In *The Trauma Question* (2008), Roger Luckhurst describes how the methodological split in trauma studies continued to grow throughout the 1990s. While the fields engaged in the treatment of trauma (e.g., psychiatry, psychology, psychoanalysis) continued to see narrative as therapeutic, poststructuralist cultural trauma theorists like Felman, Caruth, and Geoffrey Hartman tended to emphasise the fundamental incommunicability of trauma. To do so, they highlighted works of art in which conflict, irresolution, and fragmentation were dominant modes. While the poststructuralist view of trauma was already forming as Hawkins and Frank were

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[48] Theodor Adorno, 'Cultural Criticism and Society', in *Prisms*, trans. by Samuel Weber and Shierry Weber (Cambridge: MIT Press, 1981), pp. 17–34 (p. 34).

[49] Frank, p. 98.

[50] Frank, p. 179.

[51] Cathy Caruth, *Unclaimed Experience: Trauma, Narrative, and History*, Unclaimed Experience: Trauma, Narrative, and History (Baltimore: Johns Hopkins University Press, 1996), p. 7.

writing (particularly in the work of Hartman) several of the seminal poststructuralist trauma studies texts were published just after Hawkins and Frank's studies, such as Caruth's *Unclaimed Experience: Trauma, Narrative, and History* (1996). The most influential works of Hawkins and Frank are thus much more closely aligned with the therapeutic approach. In promoting a 'reparative' (Eve Kosofsky Sedgwick) way of reading illness writing, they set a precedent that profoundly shaped the emerging discipline of the medical humanities.

The success of the narrative-as-therapeutic paradigm in the medical humanities can also be explained by how it allowed literary scholars to position the emerging discipline of the medical humanities. In relation to literary studies, scholars of the medical humanities could argue (successfully or not) that they were justifying the importance of writing and the power of story. In a medical context, art therapy and the importance of helping patients express their experiences in writing made a strong case for collaboration between physicians and those knowledgeable about 'narrative'. The most important example of this argument can be found in the work of practising physician and PhD in English Rita Charon and her concept of 'narrative medicine', a highly successful methodology through which medical professionals are taught creative writing and skills of literary interpretation.[52]

Charon's work shows how deeply the approaches rooted in the therapeutic paradigm of narrative have influenced readings of illness writing. Charon does not acknowledge or cite the work of trauma theorists, but she still echoes the terms Hawkins and Frank borrowed from trauma studies when talking about the purpose of illness writing. Charon cites a provenance for her work in medical sociology,

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[52] Rita Charon, *Narrative Medicine: Honoring the Stories of Illness* (Oxford, New York: Oxford University Press, 2008).

including the work of Talcott Parsons, Arthur Kleinman, Elliot Mishler, Richard Frankel, Candace West, and Catherine Riessman among others. However, the influence of trauma studies is clear in her foundational argument that doctors' tasks 'include the duty to bear witness as others tell of trauma and loss'.[53] Like Hawkins and Frank, she argues that 'the narrating of the patient's story is a therapeutically central act, because to find the words to contain the disorder and its attendant worries gives shape to and control over the chaos of illness'.[54]

The idea that the purpose of illness writing is to overcome illness—draw lessons from it, grow as person, and re-gain a sense of agency—continues to be widely cited in the medical humanities. And for good reasons—stories of personal development still form the main narrative arc of many illness memoirs. Many people who experience or have experienced serious illness can benefit from types of art therapy in which memoir-writing is used.[55] However, many critics in the medical humanities have recently explored approaches which, in generalising terms, follow the road not taken by Hawkins and Frank in their foundational texts, taking inspiration from the critical tradition of psychoanalysis related to trauma and Holocaust studies.

As Angela Woods has argued, the influence of the work of Hawkins, Frank and others has resulted in the concept of 'narrative' coming to occupy an 'exceptionally privileged role' within medical humanities scholarship.[56] However,

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[53] Rita Charon, 'The Self-Telling Body', *Narrative Inquiry*, 16.1 (2006), 191–200 (p. 191).

[54] Rita Charon, 'Narrative Medicine: A Model for Empathy, Reflection, Profession, and Trust', *JAMA*, 286.15 (2001), 1897–1902 <https://doi.org/10.1001/jama.286.15.1897>.

[55] See e.g., Andréa A. G. Nes and others, 'Web-Based, Self-Management Enhancing Interventions with e-Diaries and Personalized Feedback for Persons with Chronic Illness: A Tale of Three Studies', *Patient Education and Counseling*, 93.3 (2013), 451–58 <https://doi.org/10.1016/j.pec.2013.01.022>; Jennifer Bertrand, 'These Roots That Bind Us: Using Writing to Process Grief and Reconstruct the Self in Chronic Illness', *British Journal of Guidance & Counselling*, 49.6 (2021), 766–79 <https://doi.org/10.1080/03069885.2021.1933382>.

[56] Woods, p. 2.

the idea of ‘narrative’ which has occupied this privileged role is a specific use of the term. As appears in the quotes by Hawkins, Frank, Nadelhaft, and Charon, in their work ‘literature’, ‘narrative’, and ‘form’, and ‘story’ are virtually synonymous. These are ordering devices, stories with beginnings, middles, and ends. This definition of narrative recalls a Victorian novel with a marriage plot or perhaps the genre of the Bildungsroman. This is also apparent in Woods’ description of narrative having the ‘principal comforts’ of ‘continuity, closure, and containment’.[57] Critics like Woods and Sarah Wasson want to keep using ‘narrative’ to mean this specific type of text with a self-contained and satisfactory plot. As Wasson writes, she ‘suspect[s] that defining all acts of meaning-making as narrative might diminish a useful specificity in the term’.[58]

However, this use of ‘narrative’ to designate something linear, realist, and teleological is rare in other areas of literary scholarship and literary theory. In fact, the use of ‘narrative’ in the medical humanities more closely resembles the traditional definition of ‘plot’ as progression and development. ‘Plotless’ texts, on the other hand, ‘lead nowhere’; to rewrite Frank’s formulation, we could say that nothing is clearly ‘gained’ in plotless texts. Literary theorists have long described plot as unfashionable, with Elizabeth Dipple arguing in 1970 that ‘plot currently has no strong place in the pantheon of acceptable literary terms’.[59] Peter Brooks elaborates the relation between plot and so-called ‘low culture’, observing that ‘plot has been disdained as the element of narrative that least sets off and defines high art – indeed, plot is that which especially characterizes popular mass-consumption

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[57] Woods, p. 8.
[58] Wasson, p. 111.
[59] Elizabeth Dipple, *Plot* (London: Methuen & Co. Ltd., 1970), p. 1.

literature: plot is why we read *Jaws*, but not Henry James'.[60] Texts that follow the teleological model do not have to be 'lowbrow', but it is simply one specific way that a text can be structured, even if it has dominated accounts of illness texts, and these comments underline how relatively uncommon this focus on story is when compared to other fields of literary study. Woods and Wasson, however, use this definition of 'narrative' to argue that we should in fact look at texts and artworks which follow different, non-narrative models. Woods suggests that medical humanities scholars draw on phenomenology as well as literary and philosophical methods attuned to 'the discontinuities and disruptions of embodied self-experience'.[61] These methods of reading, she argues, allow critics to be attentive to artworks that 'resist the principal comforts of narrative—continuity, closure, and containment—in the pursuit of the paradoxical, the ambiguous and undecidable'.[62] Types of artworks, she argues, which have not received enough attention in the medical humanities.

I agree with the argument that it is important to pay critical attention to artworks that do not follow models like Frank's 'quest narratives'. As Woods describes, the idealisation of these particular plots as more ethical than texts which are more fragmented and 'chaotic' to keep with Frank's terms, is based on an exclusionary and normative practice. Woods draws particularly on the philosophers Galen Strawson and Crispin Sartwell. In the essay 'Against Narrativity,' Strawson argues that 'narrativity' is neither an inherent human quality nor is it a necessarily ethical practice. Strawson constructs an alternative category of 'episodic' temporal orientation and identity which reflects his own experience. He argues that there are

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[60] Brooks, Peter, *Reading for the Plot: Design and Intention in Narrative* (Oxford: Oxford University Press, 1984), p. 4.
[61] Woods, p. 8.
[62] Woods, p. 8.

multiple (good) ways of being and relating to identity, some of which do not rely on storytelling, narratives of development, and meaning-finding through forms like Frank's model of the 'quest narrative'. Woods draws on Strawson's work to suggest that privileging narrative within the medical humanities 'risks mistaking a specific form of primarily linguistic expression for the master-trope of subjective experience'.[63] Wasson similarly argues that 'conventions of narrative telos are a key way that illness narrations achieve normative work' and proposes that including other critical concepts and methodologies is a way to include the marginalised and vulnerable voices which fall outside those normative understandings of illness.[64]

However, while this thesis follows the argument that we should look at texts that do not have the 'ordered' ending of Frank's 'quest narrative', I want to propose changes to the terminology used about doing so. Attempting to use terminology which more closely follows common usage in English studies, I use 'teleological plot' or 'teleological narrative' to designate plot structures like Frank's 'quest narrative', in which something is 'gained' from the experience of illness. To generalise about textual structures that do not follow this model, I use the terms 'non-teleological narrative models'. But where possible, I analyse specific examples of 'forms', following Caroline Levine's definition of 'forms' as 'patternings, shapes, and arrangements'.[65] Levine observes that 'form' is often used in two 'competing' ways: as 'an overarching textual unity (such as the marriage plot or epic)' as well as to refer to the 'many, smaller and more varied techniques that go into shaping and structuring a text (such as metaphor, the couplet, peripeteia, the cliffhanger,

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[63] Woods, p. 74.

[64] Wasson, p. 106.

[65] Caroline Levine, *Forms: Whole, Rhythm, Hierarchy, Network* (Princeton: Princeton University Press, 2015), p. 13.

monologue)'.[66] Levine favours the latter as objects of analysis, arguing that focusing on those types of form allows the critic to see literary texts as 'inevitably plural in their forms—bringing together multiple ordering principles, both social and literary, in ways that do not and cannot repress their differences'.[67]

Following Levine, this thesis charts how contemporary illness writers resist and subvert teleological plot. However, in describing how they do so, I primarily look at the 'many, smaller and more varied techniques that go into shaping and structuring a text' such as the metaphor (Chapter 2), the list (Chapter 3), and the use of forms typically associated with the workplace, such as the e-mail and the accessibility guide (Chapter 4). The form with which I started this chapter, the present-tense metatextual description of the situation of writing, is the rarest of these forms. Nonetheless, I argue that, like the other non-teleological forms on which I focus, this literary device can show us how contemporary feminist illness writers break with conventions of illness writing. Focusing on the literary devices which connect to concepts of work/labour, I argue that analysing one form at a time can help us deepen the understanding of the multiple ordering principles at play in contemporary illness texts and by extension contemporary experiences of illness.

To provide another example of how metatextual descriptions of the situation of writing connect to the development of non-teleological narrative models in illness writing, I provide a reading of passages related to ill writing and narration in Alice Hattrick's *Ill Feelings* (2021). In *Ill Feelings,* Hattrick echoes Huber's image of writing in bed, their illness provoked into a flare-up by the weather. Hattrick

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[66] Levine, *Forms: Whole, Rhythm, Hierarchy, Network*, p. 40.
[67] Levine, *Forms: Whole, Rhythm, Hierarchy, Network*, p. 40.

includes a reflexive description of the embodied situation of writing in the form of a note written on their phone:

> new note
> I cannot be anything other than horizontal, cannot go and get my laptop from the living room
> my body is so heavy, a dead weight
> darkness in the day from a storm coming is a relief, holding up my phone to make notes is too much, I can only hope I will rest and wake feeling more vertical, enough to sit up and work.[68]

The style in which the note is written mirrors the observations it contains about embeddedness in a physical and technological network. The metatextual commentary on typing foregrounds the text as shaped by a particular situation of difficult writing, which has formal consequences; the missing words and unfinished sentences suggests exhaustion and the conservation of resources and gives the fragment a poetic quality. Hattrick documents a desire to ‘be vertical’, something that is normatively associated with work, as elaborated by Cavarero’s observation of how the upright position is related to assumptions of moral *rectitude*.[69] The moment is described as an inability to work due to illness; however, by including the fragment in the finished text, Hattrick subverts this judgment. The note written in illness and horizontally becomes part of the finished literary work. This shows the difficulty of judging ‘productivity’ and challenges perceptions of what work looks like.

As in Huber’s similar passage, the snapshot of the situation of writing exists alongside a refusal of a development narrative. In another metatextual passage, Hattrick describes first attempting to write the text with a firm structure, but ending

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[68] Hattrick, p. 48.
[69] Cavarero, p. 6.

up seeing the text as more of a container which would change shape to fit its contents:

> I desired a singular narrative but the form, with its need to end in a place it did not begin, refused to accept my version of events. […] Sometimes [chronic illness] will make you think you are too well to be sick, and too sick to be well. I live in sick time, inside my loop of pain. And in that time, I gather. Science Fiction writer Ursula Le Guin thought of books as carrier bags or containers; humanity's first tools being the bag, the sack, the net, something to hold it all together, rather than weapons of domination with spear-like narratives. Carrier-bag books are 'full of beginnings without ends', holding initiations and losses, transformations and translations, containing 'far more tricks than conflicts, far fewer triumphs than snares and delusions'. If we are to recover illness from capital and from patriarchy, perhaps we need more books-as-containers, books as medicine bags, biobanks, and sick rooms. […] A sickness narrative is a useful structure, but one that could be undermined at any stage. One that insists: you can recover from this. For many of us, there will in all likelihood be no recovery. Some of us still do not know what we need to recover from.[70]

Like Huber and Khakpour, as well as for Woods and Wasson, for Hattrick a traditional 'sickness narrative' connotes a particular teleological and constraining form which is complicit with 'capital' and 'patriarchy'. It is one reason why, for example, Woods and Wasson argue that we should look to texts that use alternative models. As Matti Hyvärinen *et al* argue, the narrative turn in social sciences in the 1980s and 1990s, in which Hawkins, Frank, and Charon participated, idealises normative narrative structures and agentive, coherent—i.e., neoliberal, Western, middle class—narrative subjects.[71] Hattrick concedes that this form is something they previously desired and which can be 'a useful structure'; but argues that it simply does not apply for many people with chronic and contested/undiagnosed illness. This point is elaborated by other writers, such as in Hedva's point that Frank's description of how the 'quest narrative' is a means for those who are ill to

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[70] Hattrick, p. 210.

[71] Matti Hyvarinen and others, 'Beyond Narrative Coherence: An Introduction', in *Beyond Narrative Coherence*, ed. by Matti Hyvarinen and others (Amsterdam: John Benjamins Publishing Company, 2010), pp. 1–15.

regain a sense of coherent identity excludes many.[72] People living with mental illness or who are disenfranchised may never have had this sense of coherent identity and agency in the first place.

The passage makes clear how important it is for Hattrick and other contemporary illness writers to develop new narrative models for illness. Instead of the teleological model, Hattrick invokes the thesis of feminist science fiction writer Ursula K. Le Guin as a model for a text as a container rather than as a linear progression. This description is very close to Levine's characterisation of the literary text as 'inevitably plural'. The idea of a text as 'full of beginnings without ends' which Hattrick borrows from Le Guin is particularly applicable to the moments of reflexive description of embodied writing as moments of creative inception that form an alternative to 'ends', in both senses of the word; as endings and as purposes. Hattrick follows the passage with a proposal of the concept of 'un-recovery', a specific rejection of improvement with which they end the book.[73] Hattrick is particularly concerned with the abject experience of living with contested illness (in this case ME/CFS) or without a diagnosis. Idealisations of recovery can seem very difficult when conceived from the point of view of an illness which is not even understood or agreed to exist in medical consensus. (This experience, and the labour having a contested or mysterious illness engenders, is elaborated in Chapter 3.)

Like the passages from Huber and Khakpour, Hattrick's note undermines the idea of the 'detached' essayistic author writing from a position after the fact. In Khakpour's description, Hattrick's narrator is writing about and from the 'middle'. However, this move does not in and of itself subvert the organising power of a

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[72] Johanna Hedva, 'In Defense of De-Persons', *GUTS Magazine*, 10 May 2016 <http://gutsmagazine.ca/in/> [accessed 16 September 2019].
[73] Hattrick, p. 212.

contained ending. To show how the contemporary texts differentiate themselves from (as well as build on) earlier illness texts, I therefore compare my reading of these present-tense descriptions of situations of writing to texts that Frank includes in *The Wounded Storyteller* as examples of the 'quest narrative' and his readings of them. This shows how describing the embodied situation of writing is an established device in illness writing but also how the device in contemporary feminist illness writing, by virtue of its context, has a different effect.

Although Frank prefers 'storytelling' rather than 'writing', he in fact remarks on the existence of similar passages to the ones this chapter analyses in the texts he examines. Below I will analyse his readings of these, after which I will return to Hattrick's text and describe how attention to process differentiates my readings of these passages. Frank observes that illness writing frequently involves mention of the writing process, and how it is shaped by illness. One such moment he highlights occurs in Nancy Mairs' *Ordinary Time* (1993), a memoir about her enduring faith while living with multiple sclerosis. At the end of a paragraph, Mairs includes the following parenthesis:

> (With one of life's more excruciating perversities, the lid just popped off my daily Thirstbuster, dumping about a quart of Diet Coke onto the floor, and since I can't reach down to mop it up, I'll have to continue working on this passage with my feet in a sticky brown puddle.)[74]

Frank reads this passage metaphorically, writing that 'Mairs interrupts her story in order to display the constant interruption of her life'.[75] 'The popped lid,' he argues,

> jerks the reader back into awareness of the physical conditions that are both the topic of Mairs's writing and the means of performing that writing. Her metaphor is her story of what it is like to live in a body so disabled that she can only sit in the sticky brown puddle until help arrives. She is not helpless: her work can continue.

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[74] Nancy Mairs, *Ordinary Time: Cycles in Marriage, Faith, and Renewal* (Boston: Beacon Press, 1994), p. 184.

[75] Frank, p. 57.

> But the condition of that work's embodiment is perpetual vulnerability to interruption.[76]

Frank is attentive to the way Mairs' metatextual commentary draws the reader into her working office. In his reading, her perseverance is heroic. Despite her physical challenges, her work is where she gains and maintains her agency. It is not the difficulty of the work per se he is interested in, but the way she overcomes her challenges, and how accepting having her feet in the puddle comes to stand in for accepting living with illness and disability. In Frank's reading, Mairs' digressions mirror the disruption of illness, but the return to the teleological narrative outside the brackets also mirror the return to a normative life-story.

Frank similarly highlights a moment in Robert Murphy's *The Body Silent* (1987) in which Murphy describes how he writes despite being almost fully paralysed due to a slow-growing tumour of the spine. Murphy is able to write 'strapped in a chair, moving only his fingers over the keyboard of his computer' and Frank reads this description of his rigid writing position alongside a reference Murphy makes to the 'motionless' narration of the shamans of the Peruvian Amazon whom he studied in his career as an anthropologist.[77] In Frank's reading, the inclusion of the writing position in the teleological narrative becomes a 'metaphorical joining of his past to his present,' a narrative technique that helps re-integrate former and present selves.[78] Drawing parallels between his earlier life as an abled-bodied person and his present as someone who is disabled is a way of establishing an enduring identity, what Frank calls 'character'. 'In this display of character,' Frank argues, 'memory is revised, interruption assimilated, and purpose

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[76] Frank, pp. 56–57.
[77] Frank, p. 131.
[78] Frank, p. 131.

grasped'.[79] In Frank's reading, these moments thus become integral to the process of storytelling for integrating illness into an already existing identity and thus coming to terms with it.

In classic narrative theory, digression is what upholds structure; the delayed gratification is what makes closure, when it is finally provided, satisfactory.[80] Likeswise, Frank sees these passages as digressions which metaphorically represent the disruption of illness, while the return to a teleological narrative signals the triumph of storytelling over chaotic experiences in the writers who overcome the challenges of illness. This holds, because both Mairs and Murphy return to 'quest narratives'. At an earlier point in her text, Mairs expresses her intention with her memoir. She contrasts her initial wish when diagnosed to be 'cured' with her current wish for 'healing,' emphasising the labour involved in the latter model:

> What I had asked for was not to be freed from my limp or my nasty habits, which might be effected instantaneously, but to be made whole, which might entail collecting scattered fragments and painstakingly fitting and gluing them into place. The one occurrence is not necessarily more miraculous than the other, but the drama of it—the paralytic rising to his feet […]—distracts and delights as healing's tedium cannot.[81]

The act of 'collecting scattered fragments and painstakingly fitting and gluing them into place' has a parallel in the process of writing her long-form essayistic memoirs. It is a metaphor in which wholeness is not a restoration to a previous state before trauma. However, the image of wholeness as a typewritten glued up edited manuscript suggests a heroic effort along the lines of Franks 'quest narrative'. Both Murphy and Mairs ascribe to a therapeutic paradigm of writing, which invests these

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[79] Frank, p. 131.

[80] See e.g., Peter Brooks, *Reading for the Plot* (Harvard University Press, 1984), in which he argues that narrative 'middles' work through delay and digression which heighten the pleasure of the end when it finally arrives.

[81] Mairs, pp. 178–79.

moments of metatextual commentary on situations of writing with ideas of resilience. They can be read as instances of *working-through* both in the sense of literal perseverance through adversity and by conforming to normative 'healing' of trauma through the formulation of chaotic illness experiences into a story of triumph and overcoming.

However, in contemporary feminist illness writing, there is often no such desire for healing or narrative progression. The model Hattrick borrows from Le Guin is useful in describing a multi-pronged and sprawling text. Hattrick's text, like many other contemporary feminist illness texts, is explicitly interested in canon-building, and serves as a form of archive and bibliography over other texts with similar interests. It contains these sources, often citing them at length without analysing them or directly engaging with them. As evidence of the importance of the reflexive attention to writing positions for Hattrick, *Ill Feelings* catalogues similar moments in the texts of other ill writers. Hattrick finds similar passages in the correspondence between two ill writers, Elizabeth Barrett Browning and Mary Russell Mitford, relating to how they write: 'recumbent,' 'on a sofa instead of a chair'.[82] Hattrick also cites the entirety of a poem by Adrienne Rich, who lived with rheumatoid arthritis, from *Contradictions: Tracking Poems (YEAR?)*. The poem takes the form of a letter addressed by Rich to herself:

> Dear Adrienne,
>   I feel signified by pain
> from my breastbone through my left shoulder down
> through my elbow into my wrist is a thread of pain
> I am typing this instead of writing by hand
> because my wrist on the right side
> blooms and rushes with pain
> like a neon bulb
> You ask me how I'm going to live
> the rest of my life

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[82] Hattrick, p. 45.

Well, nothing is predictable with pain
Did the old poets write of this?
– in its odd spaces, free,
many have sung and battled –
But I'm already living the rest of my life
not under conditions of my choosing
wired into pain

rider on the slow train
Yours, Adrienne[83]

Rich's text encapsulates many of the same themes as the texts of Huber, Khakpour and Hattrick, namely the attention to the moment for writing and how it is defined by illness, as well as a deviation from any sense of the 'predictable'. Rich describes being 'a rider on the slow train', but at the same time refuses to wait for improvement, instead accepting that she is 'already living the rest of [her] life.'

In Hattrick's text, the cataloguing of this and the other passages in effect provides the bibliography that Rich searches for when she asks, 'Did the old poets write of this?' The interest in canon-building for illness writers is not new; Virginia Woolf's 'On Being Ill' (1926), often viewed as a founding text in the genre, is similarly interested in the idea of a canon of texts concerned with illness. (I will explore the use of bibliographies citation and canon-building as well as the idea of illness writing as a form of cumulative work in Chapter 5.) In *Ill Feelings*, as in many other contemporary feminist illness texts, the inclusion of other 'sick woman' ancestors describes the writers as part of a network in a way that does away with the teleological model in which the illness text is an individual's journey.

Wasson suggests drawing on affect theory and 'reading episodically,' which in her formulation is 'to read looking for a place to pause—to cease looking for the arc of the individual longitudinal journey and instead consider how a particular scene

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[83] Adrienne Rich, 'Dear Adrienne, I Feel Signified by Pain', in *The Fact of a Doorframe* (New York; London: W. W. Norton & Company, YEAR), p. 205. qtd. in Hattrick, p. 94.

constructs an emergent present'.[84] This notably contrasts with the purposes of narrative medicine and therapeutic writing about illness as described above, in which critics like Charon and Nadelhaft argue that the purpose of illness writing is to escape the 'ongoing present' and come to inhabit a sense of time that includes a past and a future. Following Wasson, I argue that we see this present-tense narration of the work of writing as an alternative mode to teleological narratives rather than a narrative interruption that ultimately works metaphorically to reinforce the sense of narrative cohesion through an ending that provides closure. It is the texts 'constructing an emergent present'. However, I argue for resisting an opposition between narrative and non-narrative literary models, instead favouring teleological versus non-teleological narrative models. Hattrick's model, borrowed from Le Guin, proves one such capacious model for the illness text as container and archive. The next section will explore the consequences of analysing the passages describing the embodied situations of writing as instances of *work* and seeing ill writers as *workers*.

Scenes of work

The inclusions of these scenes of writing in the illness texts of Mairs, Murphy, and Rich show that they are not specific to contemporary feminist illness writers. Rather, attention to the embodied position of writing has been a mainstay of illness writing. Reading more literally and materially, we can recognise these moments as instances in which the writers reflect on the labour involved in writing while ill. Mairs and Murphy are not only highlighting the illness text as a fabricated object, but one that is shaped by a particular situation of labour defined by constraint and use of technology. I propose that work—as a theme, a lens through which to look at

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[84] Wasson, p. 108.

process, and a way of reading—can illuminate these under-examined aspects of illness writing.

Woods argues for the inclusion of other, non-narrative mediums like photography, to begin 'avenues of exploration which might well intersect with or contribute to narrative but do not take storytelling as starting-point or telos'.[85] In this chapter, I argue that the passages foregrounding writing as embodied work can play this role. However, many contemporary illness writers also have a visual arts practice, the concerns of which intersect with their literary work. These visual and tactile works can form important contributions to, illuminate, and complicate the ideas set up in illness texts. A prominent example is the work of Carolyn Lazard, whose texts I also analyse in Chapters 2 and 4. Lazard is most well-known for their installations, which like photographs exists differently in time to a literary text. Analysing the way Lazard's 2020 exhibition *SYNC* play with ideas of work, I will consider how this can inform readings of contemporary feminist illness texts.

SYNC featured an artwork which forms a visual-textual parallel to the metatextual moments of narration which, I argue, relates the image of the reclined writer to ideas of work. For *SYNC*, a gallery room was furnished with objects that superficially connoted a living room: recliner chairs, air purifiers, and gas fireplace inserts were arranged to a haphazard effect around the room. Four sinks were installed vertically in the place of TVs, three hung on the walls and one arranged on a retro TV cart. Among the found objects, one piece stood out for being different. This was the only object which was 'created' in a traditional sense, rather than found and installed: a self-portrait in pen showing a figure in bed with a laptop, entitled

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[85] Woods, p. 8. A caveat here is that many photographers and photography critics discuss the narrative elements of photography.

Carolyn Working (fig. 2). The drawing embodies the tension set up by the other objects, insisting on the labour that has gone into the installation, even if it is an immaterial type of labour which is hard to visualize.

[Image removed in this version]

Fig. 2: Carolyn Lazard, *Carolyn Working*, 2020. Pen on paper, 27.94 × 35.56 cm. Installation photo, *SYNC*, Maxwell Graham / Essex Street.

Lying in bed, under duvets, with a laptop might not be the way work has traditionally been represented. Indeed, it could just as well be a scene of leisure if not for the title. I argue that we ought to see the passages of metatextual commentary on situations of writing as parallels to Lazard's self-portrait. They are scenes of writing activity which could carry different meanings (writing as leisure, writing as therapy, writing as survival), but which the authors, either explicitly or through inclusion in the texts, insist are work. By metatextually foregrounding the work 'behind' the work, the process of writing that makes the written object, the writers insist on a particular categorisation of their efforts.

As elaborated above, in traditional accounts illness writing is described as appearing almost spontaneously as a by-product of necessary psychological processes. Hawkins and Frank describe illness writing as narratives born from powerful innate impulses (Hawkins), consisting of stories told through bodies who need to testify to their experiences (Frank), or words bled onto the page (Wikan). Traditional readings of illness texts posit them as exceptionally active pieces of writing—so active that, in the most ambitious accounts (Hawkins, Frank, Charon), they can enact healing processes in the writers, readers, and, by extension, whole communities. However, the processes they participate in are not conceptualised as *work*. Contemporary feminist illness writers make it clear that their texts must be read differently; they must be read as laboured-over texts, outcomes of the work of writing while ill. In Boyer's essay 'Woman Sitting at the Machine' quoted in the Introduction to this thesis, she describes the layers of effort (specifically, work) entailed by illness: 'You do the work of being sick, the work of trying not to be sick anymore, the work of going to work while sick, the work of what is unpaid work, also'.[86] Hattrick echoes this in commentary on the writing of Alice James: 'Illness was her occupation, because illness takes up time, the time of not-doing what you want to be doing, the time of explaining why it has taken you a year to reply to a letter'.[87] Similarly, Huber describes her illness as 'its own work, only this work must be done in the opposite way that other work is done'.[88] Writing while ill is not simply having two experiences at once. Effort layers, and when illness and work intersect, they compound each other.

These contemporary writers posit writing as a physical, cerebral, and emotional kind of work. In *Narrative Medicine* (2008), Charon acknowledges that this is the case; she observes that the work she is asking of healthcare workers when doing 'narrative medicine' is extra labour, requiring time, effort, and emotional investment. She describes how a group of third-year medical students assigned to her course 'were just too exhausted to contemplate the emotional demands' of her exercises.[89] 'I had to accept,' she writes, 'the observation that narrative writing places a significant demand on the student'.[90] But Charon neither develops the implications of this nor looks at the same issue from a patient perspective. I argue that the passages describing the embodied situations of writing analysed in this

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[86] Boyer, *A Handbook of Disappointed Fate*, p. 171.
[87] Hattrick, p. 51.
[88] Huber, p. 49.
[89] Charon, *Narrative Medicine*, p. 157.
[90] Charon, *Narrative Medicine*, p. 157.

chapter show that the same is true for those who are ill; writing requires many kinds of energy and writing while ill is a specialised and doubly hard process.

The effort and skill required as an ill writer and artist is also invoked in other ways in Lazard's *SYNC*. In an untraditional move, the 'press release' sent out to advertise the exhibition almost entirely consists of the short story 'And the Sun Still Shines' (2012) written by the late disability and illness advocate Tameka Blackwell.[91] Blackwell's story is about the difficulty of finding time to write between unwanted interruptions; how being ill and disabled complicates creative work, which must always be done against a background of chronic pain and discomfort, as well as literally between appointments and care schedules. Like Frank, it is possible to read the moments of breaking away from narrative to comment on a writing position as metaphors of a contingent and constantly interrupted life. However, as the texts by contemporary writers do not have a clear narrative to break away from—Huber's book is a collection of essays and poetry, Hattrick's text ends with no resolution—the shifts in tense, hyperlocal descriptions and inclusion of quotes and fragmentary notes are the substance of the text rather than digressions from it.

Foregrounding the effort involved in illness writing is a way of showing that it is skilled work, the achievement of which should be recognised. If it is seen as simply part of a therapeutic process, it becomes easier to dismiss the artistry and remuneration of this kind of work. This is an issue which applies to work that is seen as stemming from a 'natural instinct' or which is seen as intrinsically rewarding,

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[91] Carolyn Lazard, 'Press Release for Carolyn Lazard's Exhibition SYNC' (Essex Street/Maxwell Graham, 2020) <https://maxwellgraham.biz/wp-content/uploads/2021/08/PressRelease.pdf> [accessed 7 June 2022].

such as creative work.[92] Care work, for example, has also historically been seen as more 'natural' for women, an argument used to devalue the skill involved and lower remuneration.[93] Sarah Jaffe calls this the 'labour of love ideology': that workers in, for example, the art world, academia, teaching, care work, and the charity sector are expected to tolerate lower pay and more precarious working conditions because they supposedly work with what they love and/or have a natural predisposition for.[94] The idea that authors write for therapeutic reasons can similarly imply that because they get something out of it, their achievements do not need to be recognised, something that in turn can be used to justify low royalties and speaker fees. This affects ill writers, who are likely to be in precarious situations, even more adversely.

Going back to the healing paradigm in trauma studies in which Hunsaker Hawkins and Frank's works participated, something similar was observed at the time. The main critique of the healing paradigm of trauma in the wake of the inclusion of PTSD into the *DSM* was that it redefined Vietnam veterans from political agents to individualised patients. Moving them from the streets, where they gathered *en masse* to demand an end to war and torture, and into individual treatment rooms was seen as a way of disenfranchising the veterans.[95] The veterans were organised through the Veteran's Association (VA), but this was a state-governed organisation that primarily had their employer's, i.e., the state's, interests at heart. (The VA in fact opposed the inclusion of PTSD in the *DSM*, for reasons that some

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[92] Dorinne Kondo, *Worldmaking: Race, Performance, and the Work of Creativity* (Duke University Press, 2018).

[93] Sarah Jaffe, *Work Won't Love You Back: How Devotion to Our Jobs Keeps Us Exploited, Exhausted, and Alone* (New York, NY: Bold Type Books, 2021), p. 22; Stephanie Coontz, *The Way We Never Were: American Families and the Nostalgia Trap* (New York: Basic Books, 1993); Raj Patel and Jason W. Moore, *A History of the World in Seven Cheap Things: A Guide to Capitalism, Nature, and the Future of the Planet*, First edition (University of California Press: University of California Press, 2017).

[94] Jaffe.

[95] Kalí Tal, *Worlds of Hurt: Reading the Literatures of Trauma* (Cambridge: Cambridge University Press, 1995).

scholars describe ‘can be attributed in part to an anxiety about its own complicity in encouraging traumatized soldiers to return to conflict and its failure to adequately treat traumatized veterans’.)[96] While it was undoubtedly good that treatment was developed and became available for those living with the consequences of trauma, it is worth keeping this critique in mind. Zaretsky similarly observes how the influence of psychoanalysis has contributed to a view of the personal responsibility for working through issues, positioning a ‘process of inward development’ as ‘the only secure basis for progress’ in a way that neatly supports capitalist idealisation of autonomy and personal agency.[97] By individualising treatment, political momentum was lost; rather than focus on the structural causes for the soldiers’ trauma, the focus turned to each individual’s responsibility for their own healing journey.

I argue that by calling attention to their writing as work rather than therapy, ill writers attempt something like a reversal of the political re-definition seen among veterans: this time moving from ‘patient’ to ‘worker’ status. The texts participate in a longstanding feminist tradition of calling attention to the existence and skill of work that is not normally recognised as such. As *Wages for Housework* showed, when groups with little political legibility claim the subject status of worker, it helps establish them as politicised subjects. Being a worker means having access to a history of organising victories and a vocabulary of resistance (see also Chapter 3). Workers *work*, of course, but they also organise into unions, elect union representatives who connect daily issues to their larger political contexts, strike and take other forms of industrial action. In short, they have the power to demand better working conditions. ‘Patients’ do not have this same collective power. The

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[96] Bond and Craps, p. 36.
[97] Zaretsky, p. 27.

ramifications and challenges of this will be explored in Chapter 2 regarding patient work and the 'proactive' patient role and in Chapter 3, on the illness-as-work metaphor (rather than illness *writing* as work). The political affordances of the metaphor and its extension as writers play with the idea of collective writing as organising will be explored in Chapter 5, on post-work theory. The point I make here is that there is much at stake in claiming to be an ill *writer* rather than simply a patient who *seeps text*.

Returning to Lazard's exhibition for a moment, I want to elaborate one more way in which it explores the relation between form and labour in a way that can illuminate the work done by illness texts. Work is not only a theme, but can be a methodological lens, as has been shown by Sianne Ngai. Ngai describes how capitalistic understandings of effort and value are at play in aesthetic judgments. Lazard's sinks invoke Marcel Duchamp's most famous 'readymade', *Fountain* (1917), a found object which becomes art by virtue of being installed in an art setting and labelled as such. Sianne Ngai describes the readymade as the ultimate gimmick, theorised in her work as a capitalist form that draws attention to labour by 'strik[ing] us as working too little (labor-saving tricks) but also as working too hard (strained efforts to get our attention)'.[98] The readymade elides labour, and can be seen as indicative of laziness in the artist, who has resorted to other people's work rather

[Image removed in this version]

Figure 3: Installation photo, Carolyn Lazard, *SYNC*, 2020, September 10 - October 17, 2020, Maxwell Graham / Essex Street.

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[98] Sianne Ngai, *Theory of the Gimmick: Aesthetic Judgment and Capitalist Form* (Cambridge: Belknap Pres, 2020), p. 1.

than producing something new; at the same time, the readymade can feel heavy-handed, its message almost crude in its simplicity (here, the TV as a 'time sink').

The two recliners in Lazard's installation are arranged in ways that play with this same tension between indulgence and exertion, one reclined to an extreme position (entitled *Lazy Boi*) and the other almost upright, as if having expelled whoever had been sitting in it. As the gallery label describes, the upright recliner is an assistive device, a power lift chair designed to help people who cannot rise from a chair on their own. However, the title of this chair, *Piss on Pity*, suggests a negativity in how this assistive device is seen by others. The installation explores these two positions—fully-supported recumbence or upright exertion—which in turn can be related to the paradoxes of living with chronic illness, i.e., fluctuations between relapse and remission and constantly changing support and care needs. The positions of the two chairs can also indicate conflicting representations of the chronically ill person, accused in mass media and political narratives of being propped up by public support, but by their own description constantly being pushed forward to do more and exerting themselves to the point of worsening their conditions.

Lazard's self-portrait provides a contrast to the readymades as a more traditional framed drawing, but it also 'avoids' work in several ways. It is very simple, as a line drawing on paper. Moreover, the self-portrait does not show a situation of creating that portrait (instead showing the artist on their laptop), suggesting a form of mediation. The self-portrait is drawn from imagination, drawn by someone else, drawn using another model, drawn based on a photo taken by someone else, or using a delayed timer. Like the use of found objects (associated with the readymade, as well as with later art movements like the socialist *arte povera*) this elision contains a suggestion of more truncated labour, either left out or avoided, using assistive devices or the help of someone else. The installation challenges assumptions about what work looks like and how effort is dismissed due to prejudices around what is and is not seen as legitimate and productive behaviour.

In the context of Lazard's exhibition, Tameka Blackwell's short story inserted into the press release can be read as a kind of readymade in the sense of a found object, placed within a new context created by the artist. It is the result of another person's labour placed where the artist's own labour (or in this case, the gallery curator's) is typically expected to be. However, the story, which is about solidarity and collaboration, suggests that this borrowing of labour is a form of collaboration. The press release mirrors the exhibition in making visible how engaging with others is unavoidable within a context of illness and disability. This has a parallel in how Huber's narrator describes her ill writing practice as embedded and cyborg-like.

In Lazard's exhibition, the readymade, one of which is a literal reclined chair, becomes a form that visualizes interconnectedness and *reliance*—on other people's labour, assistive devices, artistic forms, other artists, and artworks. This is a practice more common in visual arts than in literature, it being common knowledge that many of the most famous artists have/had large studios, with the apprentices and other paid workers doing most of the work ascribed to the artist.[99] There is a tradition of artists using other people's labour as a key aspect of their practice, a tendency Leigh Clare La Berge has called 'decommodified labour'.[100] But likewise, I argue that we can see the practice of long quotations, like Rich's poem inserted into

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[99] See Peter Paul Rubens, Andy Warhol's Factory, or Jeff Koons. Of course this is also the case in literary production, such as in the ghostwriting of celebrity memoirs, as well as in the contributions of agents, editors, and marketers, but is less often something which critics remark on.

[100] Leigh Claire La Berge, *Wages Against Artwork: Decommodified Labor and the Claims of Socially Engaged Art* (London: Duke University Press, 2019).

Hattrick's texts almost without commentary as a way of 'borrowing' labour, and this forms part of a development of an ill aesthetics. The use of old notes, inserted supposedly without editing, in both Huber and Hattrick's texts, work in a similar way.

Illness writing's detractors have taken a more negative approach to what I read as deliberate embeddedness and interdependence when characterising it as a genre that often takes the easy way out. In a recent essay about the fragmentary essay-memoir about illness, Houman Barekat laments the popularity of what he calls a 'genre of affliction,' which in his opinion is often 'gimmicky' and 'insubstantial'.[101] While conceding that 'the fragmented, non-linear memoir format lends itself to telling stories of trauma and mental ill health, insofar as it transposes onto the page the associative and disordered thought processes of an unsettled mind,' he writes that the format has been repeated so often that it now only induces 'weary, eye-rolling cynicism' and 'readerly fatigue' in him.[102] He argues that the format of mixed forms, personal vignettes, and extensive references to other illness writers (Virginia Woolf in particular) as well as 'nuggets of cultural history or literary criticism pertaining to said ailment' is a cover-up for a lack of actual literary value; in his words, 'a neat workaround' for writers without much material.[103] In fact, the genre's ubiquity, he argues, is the result of both readerly and writerly laziness; illness memoir at its worst is 'a cloyingly sycophantic form: the judicious sprinkling of erudite tidbits flatters the reader into feeling like they're engaging with a work of depth and substance, rather than an extended musing'.[104]

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[101] Barekat. No pagination.
[102] Barekat.
[103] Barekat.
[104] Barekat.

Likewise, Michael Bise criticises the work of artist and writer Taraneh Fazeli, who works with many of the same themes as Lazard—chronic illness, 'an ethics of care emerging from disability justice that values interdependencies and dependencies'—of being gimmicky.[105] In an essay, he accuses her work of being 'intellectually lazy' and 'an example of the kind of fuzzy thinking that too often goes unchallenged in the art world'.[106] Bise's argument, like Barekat's, is that contemporary artistic work about illness is too reliant on cliché and citation; he writes that 'throughout the essay, Fazeli throws around the kinds of loose, inaccurate phrases we have become so used to seeing we hardly think to question anymore'.[107]

Barekat and Bise accuse contemporary illness writing of being gimmicky—of, in Ngai's helpful elaboration of this response, taking too many short-cuts while at the same time 'making untrustworthy claims'.[108] They argue that the artworks are formulaic; they present similar ideas, use similar forms, and rely on extensive quotations from the same authors. To some extent, I would agree: the writers employ extensive quotation, inclusion of unedited notes, and the refusal of development narratives, which, as Freud pointed out, require labour from the teller. My argument, however, is that this is intentional, and a core part of the writers' practice. When the memoirs refuse to do 'a good job' of being illness memoirs, as measured against traditional expectations, this is a strategy that illuminates the way in which ideals of labour are at play in aesthetic judgments. The texts refuse to resolve their experiences into a neat lesson, or a story about strength and the overcoming of

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[105] Taraneh Fazeli, 'Notes for "Sick Time, Sleepy Time, Crip Time: Against Capitalism's Temporal Bullying" in Conversation with the Canaries', *Temporary Art Review*, 2016 <http://temporaryartreview.com/notes-for-sick-time-sleepy-time-crip-time-against-capitalisms-temporal-bullying-in-conversation-with-the-canaries/> [accessed 13 October 2020]. No pagination.
[106] Michael Bise, 'Snake Oil: Taraneh Fazeli, Critical Writing Fellow, Core Program', *Glasstire*, 2016 <https://glasstire.com/2016/05/09/snake-oil-taraneh-fazeli-critical-writing-fellow-core-program/> [accessed 13 October 2020]. No pagination.
[107] Bise.
[108] Ngai, *Theory of the Gimmick*, p. 3.

obstacles, through discipline and perseverance. The combination of grandiose claims and supposedly labour-saving formal devices call into question ideals of work, including how they inform the way we read texts.

Barekat argues that writers fail to provide ‘insight’ and ‘elucidation’, and Bise argues that Fazeli serves other patients badly by valorising ‘weakness and passivity’.[109] This very closely matches up to the intentions that the writers state for their literary texts, such as Huber’s claim that she refuses to ‘f[i]nd lessons to extract’ from her chronic illness.[110] The texts refuse labour in a multitude of ways, which can be as simple as Huber writing, in an essay which constantly varies its form, alternating traditional prose and various line breaks:

> There’s a theory about the ‘gates’ of pain in
> the brain that shuttle signals,
> but I can’t look it up right now.
> I can do only certain kinds of thinking in pain.
> I can think through a keyhole.[111]

She insists on writing from a situation shaped by illness, and to let this situation shape the text in turn. She refuses to go back later to chase up the reference, instead preserving the ‘failure’ in capacity, and asserting that her ‘fuzzy thinking’ is good enough. (I explore this idea of the withdrawal of labour formally and politically in Chapter 2, on work-related illness metaphors, and in Chapter 5, on the knowledge produced by illness.) There is a direct link between passages describing the embodied labour of the process of writing about illness, and the use of formal devices that undercut normative expectations of the ‘work’ expected by the texts. Rachel Greenwald Smith has argued that a traditional novelistic plot, which requires

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[109] Barekat; Bise.
[110] Huber, p. 46.
[111] Huber, p. 49.

a readerly investment up front, and is then repaid through a story of personal development and a satisfactory ending, is complicit in a neoliberal investment-and-return logic.[112] Ngai, in *Ugly Feelings* (2007), argues that novels can undermine this repayment of positive affect as a way of momentarily stepping out of a capitalist logic.[113] I argue that the contemporary illness writers I analyse in this thesis do the latter.

I argue that the passages therefore link the formal properties of the texts to their political opposition to ideals of work (to be explored further in Chapter 5). The metatextual commentary on how illness shapes the situation of writing is one of several ways in which contemporary feminist texts play with the ways in which literary forms can invoke aesthetic judgments related to effort and work. Sometimes being chronically ill means doing a lot, sometimes very little. Sometimes there is capacity for grand claims; sometimes all that is possible is an awareness of where the writer is, and how difficult writing is at that moment. By juxtaposing these modes, the writers allow them to coexist, and trial new ways of working, around the ill body rather than against it. ‘Work’ is no less expansive a concept than ‘narrative’, but it is one that the texts point to as structuring their creation and their inquiry, and a concept invoked as part of a claim to political agency.

Partial perspectives: working from the sickbed

Exhibited in the first year of the Covid-19 pandemic, Lazard’s *SYNC* must be considered in the context of changes in work environments incited by the necessity for many of working from home. The scene Lazard draws attention to as work was

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[112] Rachel Greenwald Smith, *Affect and American Literature in the Age of Neoliberalism* (New York: Cambridge University Press, 2015).
[113] Sianne Ngai, *Ugly Feelings* (Cambridge: Harvard University Press, 2007).

no longer uncommon, as isolation measures and preventative strategies found many temporarily working from bedrooms. *Ill Feelings* was also written during the pandemic and describes how Covid changed the role of the chronically ill artist within the culture of work. Hattrick also uses the present tense for this passage, describing the experience as it is unfolding:

> Anxiously made plans to attend conferences and trips to archives and libraries are cancelled. Initially this is disheartening, but those feelings quickly turn to relief. I do not have to find the energy to go anywhere at all. All the things I have put off for months because of fatigue suddenly can't happen. Everything now needs to be done from bed—including all the research I have left to do. No visiting libraries, no ordering archive material. I must rely solely on digitized documents, online articles, remote interviews—as I am used to, with so little energy to spare. The world has slowed down to meet us—and it has also migrated. My way of researching and writing—as much from bed, from home, as possible—is the new normal.[114]

Writing horizontally, and from bed, is suddenly common: not a mark of pathology but a result of one. Hattrick describes the surprise of seeing their work routines and work positions become general, as the rest of the world of work comes to look like that inhabited by the ill writer. The ill writer is no longer at a disadvantage; for a moment, they have the most experience of how to navigate the situation, having already developed strategies for working from home under unpredictable circumstances.

Ill and disabled people expressed ambivalence about the changes in work norms brought about by the pandemic. Initially, many were pleased about the sudden accessibility of events, which were being moved online due to the pandemic, but were also frustrated at how quickly accessibility accommodations they had been denied for years suddenly were implemented when required by the able-bodied population. Moreover, the fact that many disabled and chronically ill people were

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[114] Hattrick, p. 195.

particularly vulnerable to Covid-19 infection, and therefore asked to stay home even as isolation measures were gradually lifted meant that the pandemic had especially adverse and extreme effects for groups who were already marginalised due to unhealth and disability. As of spring 2023, many immunocompromised and disabled people are still having to isolate more strictly than they did before the pandemic and experience their wellbeing as having been sacrificed in decisions to return to the able-bodied 'normal' of in-person events, non-masking, and in-office requirements.

Leah Lakshmi Piepzna-Samarasinha describes how disability justice activism allowed her to understand that writing from her sick bed did not mean she was 'weak or uncool or not a real writer' but rather that it was 'a time-honored crip creative practice'.[115] Writing consciously from her bed also allowed her to inhabit ill positionality, 'to finally write from a disabled space, for and about sick and disabled people, including [her]self, without feeling like [she] was writing about boring, private things that no one would understand'.[116] Piepzna-Samarasinha later describes her bed as her 'office.'[117] This image also echoed by other sick and disabled artists and writers in the publication *Bed Zine* (2021-). In a text by Phiroozeh Petigara, the narrator describes teaching yoga from her bed but fearing that her students will discover her location, before making peace with the fact that her position is integral to her practice.[118] The initial shame of working from bed connects to the anxiety Piepzna-Samarasinha indexes, of not being a 'real writer' or worker. The three issues of *Bed Zine*, each featuring about 25 different ill and disabled artists' work on their relationship with their beds, contribute to countering this prejudice, and situating the bed as an important creative location in ill and disabled art practices.

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[115] Piepzna-Samarasinha, *Care Work*, p. 17.
[116] Piepzna-Samarasinha, *Care Work*, p. 17.
[117] Piepzna-Samarasinha, *Care Work*, p. 181.
[118] Phiroozeh Petigara, 'Love and Cortisone', *Bed Zine*, 2022, pp. 29–31.

The metatextual description of a writer's embodied position as they are writing is not just a political act but also a way of attending to how and from where knowledge is produced. As a form of reflexivity, it builds on the feminist epistemology originating in second-wave feminist philosophy and which has formed the theoretical basis for fourth-wave feminism. Building on Black feminist thinkers including 'The Combahee River Collective Statement' (1977) which pointed out the compounding oppression faced by Black female workers, feminist thought became interested in how knowledge produced from a marginalised perspective could be more comprehensive than that produced at the traditional centres of knowledge. Through explication of how the historically, embodied, and socially situated position of an epistemological subject influences the creation of knowledge, feminist epistemologists including Donna Haraway and Joan Scott challenged the idea that knowledge can ever be 'objective'.

Much of the writing associated with this reflexive tradition embeds metatextual moments on the situations of writing to make their point. Rich's 'Notes toward a Politics of Location' (1984) argues against white Western feminists invoking a 'universal womanhood' in favour of more specificity in how gender-based oppression affects women differently depending on a multitude of factors. The essay includes a metatextual description of trying to write the text at home, being interrupted by a bumblebee, and leaving for a café to work.[119] In order to locate her own *positionality*, she needs to be attentive to her own physical presence and begin 'with the geography closest in—the body'.[120] Specifically *her* body; she wants to be

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[119] Rich, 'Notes toward a Politics of Location', p. 211.
[120] Rich, 'Notes toward a Politics of Location', p. 212.

reflexive about her positionality, but without centring herself and her feelings within a broader understanding of feminism.

Not all life-writing is reflexive—there are biographies and autobiographies in which (auto)hagiography dominates—but reflexivity as a mode and life-writing as a genre often overlap and complement each other. Many illness essays bear a close resemblance to the reflexive academic feminist epistemological work of scholars such as Liz Stanley or Tina Campt. Stanley argues that reflexive autobiographical narratives can describe a self that is ‘much more complexly constructed and more aware of its internal fractures’ than poststructuralist feminist analysis had previously admitted.[121] Passages on the situation of writing foreground the texts’ participation in the creation of embodied and ‘partial, locatable, critical knowledges’, as Donna Haraway describes a feminist approach of situated knowledges in her essay from 1988.[122] Campt, for example, includes the embodied experience of working in archives, and the tactility of photographic negatives in her examination of historical Black British vernacular photography. Knowledge that is ‘unlocatable, and so irresponsible,’ Haraway argues, is ‘unable to be called into account’—texts which clearly situate themselves, on the other hand, create knowledge which is transparent about its own origins.[123]

Huber emphasises how she writes from a partial and embedded point of view in the experience of illness:

> I lie here, trying in a half-hearted way to respond to work emails.
> I’m getting stuff done, and then I’m resting, by the
>   light of this red flashing light [i.e., chronic pain],
> and although there is a glare, this is my life. This is my *normal* […].

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[121] Liz Stanley, ‘The Knowing Because Experiencing Subject: Narratives, Lives, and Autobiography’, *Women’s Studies International Forum*, 16.3 (1993), 205–15 (p. 213).
[122] Haraway, p. 584.
[123] Haraway, p. 583.

> I come to know this pain that surrounds me because I have to keep my hate in check. Pain is my very flesh. There's no 'brave battle' here. I refuse to be at war with myself. I just am.[124]

Overcoming her illness is not an option; living in the moment with it is all she can do. The several metaphors here layer on top of each other. Pain is 'flesh', continuous with the narrator's body. It is also a 'flashing light', the flashing on and off representing the movement between 'getting stuff done' and 'resting'. The observation that there is always a 'glare' from the light of the pain invokes a metaphor which acknowledges vision as mediated through the mechanics of the body. In Haraway's terms, this provides 'the view from a body, always a complex, contradictory, structuring, and structured body' rather than 'the view from above, from nowhere, from simplicity'.[125] It is the hyper-specific which, according to Haraway, makes possible the creation of communities, 'connections and unexpected openings'. [126]

The passages commenting on the position in which the author is writing situate the texts in particular locations. As Haraway writes, '[feminist objectivity as positioned rationality's] images are not the products of escape and transcendence of limits (the vision from above) but the joining of partial views and halting voices into a collective subject position that promises a vision of the means of ongoing finite embodiment, of living within limits and contradictions—of view from somewhere'.[127] The description of brain fog, physical pain, and exhaustion describe the ways in which the texts are written with 'partial views' and with 'halting voices'. The inclusion of the ways in which the writers are embedded with technology

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[124] Huber, pp. 57–58. Emphasis in original.
[125] Haraway, p. 589.
[126] Haraway, p. 590.
[127] Haraway, p. 590.

foregrounds the ways in which a text is created not only by a subject but through a complex network of factors and through technological mediums which not only shape the texts but enable their writing.

The criticism of universality also concretises one of the differences between a feminist epistemology and, for example, Arthur Frank's argument that through illness writing, patients can become 'dyadic,' communicating bodies, the highest ethical narrative practice in his view. In *The Wounded Storyteller*, Frank writes that 'the ill person who turns illness into story transforms fate into experience; the disease that sets the body apart from others becomes, in the story, the common bond of suffering that joins bodies in their shared vulnerability'.[128] While his points are salient, rhetoric like 'bodies in their shared vulnerability' lacks attention to the differences that exist, and which shape specific experience of illness. The philosopher Marina Vishmidt criticises the ubiquitous language of 'bodies' for glossing over categories of race, ethnicity, nationality, sexuality, disability and so on.[129] The body is not a universal equalizing condition, as she argues; presently, bodies are segregated into populations that are treated differently, and whose material, cultural, and social circumstances influence the illnesses they get and the treatments they have access to. Contemporary feminist illness writing instead provide embodied, partial, situated, locatable knowledges which reverse the direction of knowledge and authority (patient to doctor, disabled to able-bodied).

In this chapter, I have argued that the moments describing the embodied labour of writing are useful as objects of study that represent an alternative to developmental arcs and stories of growth. Writers are increasingly rejecting

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[128] Frank, p. xi.

[129] Marina Vishmidt, 'Bodies in Space: On the Ends of Vulnerability', *Radical Philosophy*, 208, 2020, 33–46.

teleological narrative structures. One reason is that a narrative structure that depicts positive development often does not reflect the experience of living with chronic illness. As Wasson writes, ‘many people living with chronic pain report that they are excluded, marginalised and disregarded, and a key part of this vulnerability stems from narrative transgression, the way they may not be able to adopt the proleptic subjectivity attendant on a particular teleogenic narrative’.[130] However, writers experiment with other narrative forms; the ‘carrier-bag model of narrative’ which Hattrick borrows from Le Guin or the spatial model enacted by Lazard’s exhibition are more typical of the narrative models of juxtaposition seen in contemporary illness writing.

Contemporary feminist illness writing, which typically refuses both narrative conventions and the idea of the text as ‘healing’—and which often blends art forms and transcends the singular text by being supplemented by visual art practices, tweets, blogs, updated versions and more—invites methodologies attentive to a multitude of different forms. This emphasis on process is also why I have chosen the terminology of ‘illness writing’ over the traditional term associated with Hawkins and Frank, ‘illness narrative’. This indicates a shift towards process over finished text and writing as a verb rather than as a noun. Moreover, it steps away from specific uses of ‘narrative’ as a structuring force.

As texts describing their own process of creation, the illness texts and exhibition analysed in this chapter can be compared to a trend of contemporary novels in which the failure to write a novel becomes the plot of the novel.[131] By bringing attention to specific bodyminds as they are writing, the authors make visible

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[130] Wasson, p. 107.

[131] Rachel Sagner Buurma and Laura Heffernan, ‘Notation After “The Reality Effect”: Remaking Reference with Roland Barthes and Sheila Heti’, *Representations*, 125.1 (2014), 80–102.

the degrees to which their support system, class status, nationality, and other external factors are enabling their writing. This draws attention to the fact that even if we see writing as therapeutic, it is a type of therapy available only to some patients: the patients who have the time, support, and educational level that allows them to do so on their own or who have access to the art therapy programmes which are more likely to be available at high resource healthcare institutions. Calling attention to the effort of writing thus calls upon questions of access, a concept that will be elaborated in Chapter 4.

It is true that writing can be a ‘healing’ practice. However, analysing illness writing through this lens focuses on only one aspect of the texts. Moreover, looking at the experience of illness as a conundrum which each person must process on their own puts the onus on the individual; art therapy is an individual solution to what, as the texts describe, are often structural problems. Describing illness as work is useful to these writers, I argue, because invoking concepts of employment serves as a way of taking a structural view on the factors that shape illness; constructions of the ‘sick role’, clinical expectations of patients, and economic understandings of the ill body. Moreover, work is a concept and a framework that comes with opportunities to resist the status quo; if the sick woman is a worker, she can draw on the repertoire of labour activism, go on strike, or organise with others into a union. Drawing on the register of work invokes a certain power, which will be elaborated further in the next chapter, which looks at the metaphors of illness as work. I use these metaphors to explore a more concrete sense in which illness is work, the ‘patient work’ entailed by illness.

Chapter 2: The work metaphors of illness

The author Esmé Weijun Wang compares the management of her chronic Lyme disease (as well as multiple mental illnesses) to the precarious editing career she had before becoming ill. In periods when her symptoms are serious, she writes:

> My work, although it may not look like work to most, is to take care of myself. I must care for my health with as much attention as I once paid to the documents I was hired to edit. Aggressive pursuit of one's ambition is a skillset that, I hope, has not left me. In the meantime, I am aggressively pursuing a dream of recovery.[1]

Wang's essay problematises the work ethic that, while she could still work, drove her to wake up at '4 a.m. every morning' and drink 'enough coffee to cause spontaneous, caffeine-sick vomiting up to three times a day'.[2] She describes how she was driven to transgressing her own boundaries and working to the point of collapse by internalising a capitalist idealisation of productivity. She is aware of where this mindset comes from but still feels shame related to her chronic illnesses: 'in a society that holds productivity as unequivocally good, to do less feels like a moral failing', she writes.[3]

However, while critiquing these norms, Wang uses the same register of single-minded ambition to describe the way she is now 'aggressively pursuing' getting better, describing it as a 'skillset'. The passage sets up illness as a state where normal work may be suspended, but also a state which can be used as a training ground for employment—with the right mindset. Even in illness, ambition can be developed and skills can be honed or maintained. Or at least on the surface; the interjection of 'I hope' indicates doubt. The passive construction also betrays some

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[1] Wang.
[2] Wang.
[3] Wang.

insecurity as it sets up ambition as a skillset that can simply leave on its own accord, positioning the subject as unable to control this. What Wang is 'aggressively pursuing' is a 'dream', after all, a word choice that reinforces the apprehension of how far a work ethic and ambition can carry her. Additionally, the editing work to which she compares the management of her illness is precarious work; an arts career that carries prestige but lacks job security and has low pay. Is the comparison here that both editing and illness require hard, relentless work, with little predictable outcome? Wang describes how recasting her illness, and her attempts at recovery, as *work* can help legitimising her state for others and herself, but also indicates the limits of this metaphorical language.

In the Introduction to this thesis, I described how work has become a ubiquitous metaphor in contemporary illness writing. Wang's description of taking care of herself as a job recalls but also contrasts with Audre Lorde's description of self-care as a form of warfare. Lorde famously wrote that as a queer Black woman, 'Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare'.[4] When the odds are stacked against you, the act of survival can be radical. The metaphor of self-care (in the sense of managing symptoms) as *work* carries different connotations; it describes the work of illness as requiring dedicated and focused energy but also as a state that is vulnerable to exploitation and precariousness.

Chapter 1 argued that metatextual descriptions of the situation of writing, and emphasis on being in the 'middle' of a traditional story structure, writing texts which will not and cannot come to a closure, are some of the strategies employed by contemporary feminist writers to resist teleological narrative. I argued that

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[4] Lorde, p. 130.

foregrounding process is a way for authors to position themselves as *workers* rather than *patients*, with an artistic and political project that exceeded their own individual healing and development. However, while the focus on the laboriousness of writing is a subtle way of doing this, the claim to being a worker is often much more overt, as Wang's essay shows. This chapter looks at the ubiquitous metaphor of illness as work—specifically, a type of job—and how contemporary feminist illness writers such as Boyer, Wang, Huber, Lazard and Khakpour take up this metaphor to tell non-teleological stories about illness.

How and why does illness feel like work? And *which kind* of work does it feel like? As described in Chapter 1, the contemporary experience of chronic illness is often one of navigating flare-ups and symptoms while having to work at the same time. And having to work while being ill is in addition to all the labour that is *entailed by* illness. Social scientists call this *patient work,* something that includes tasks such as managing symptoms, going to appointments, sorting out bureaucracy related to treatment and insurance, liaising with potential employers, coordinating information shared between different healthcare providers, organizing support from friends and family, enacting lifestyle changes, and learning about the condition and treatment at home.[5] I argue that the rise in figuring illness as a type of job is related to a historical increase in the labour entailed by illness and the complexities of an increasingly 'proactive' patient role. The medical sociologist Carl May observes that since the 1960s, healthcare providers and healthcare policy have reconfigured the 'business of being a patient,' progressively shifting ever more of 'the burden of *work*

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[5] A. L. Strauss and others, 'The Work of Hospitalized Patients', *Social Science & Medicine (1982)*, 16.9 (1982), 977–86 <https://doi.org/10.1016/0277-9536(82)90366-5>; Richard J. Holden and others, 'SEIPS 2.0: A Human Factors Framework for Studying and Improving the Work of Healthcare Professionals and Patients', *Ergonomics*, 56.11 (2013) <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3835697/> [accessed 2 June 2023].

of caring, managing and organizing experiences of chronic illness out of formal healthcare systems, and into the remit of people who have chronic illnesses themselves'.[6] Chapter 1 examined what we might, using May's terminology, call 'the burden of *work* of […] organizing experiences of chronic illness'. This chapter looks at work that falls under May's header of the burden of 'managing' illness.

However, as this language shows, using metaphors drawn from a register related to work does not have to subvert a teleological narrative structure or neoliberal values. Describing patienthood as a 'business', in which one develops the skill of 'self-management' and 'aggressively pursu[es] a dream of recovery' borrows from registers and fields in which growth and a particular upwards trajectory is desirable. Some writers and advocates engage with this sense of illness as work: of illness as a skill, an active process, and describing illness as work as a way of claiming legitimacy in the face of marginalisation and prejudice. Other writers, however, have responded to these metaphors by imagining illness as work in a different sense: as precarious work, work in which advancement is structurally foreclosed, and by elaborating related metaphors of ill unions and illness as industrial action. I argue that this latter version of the illness-as-work metaphor is closely related to the non-teleological forms at play in the texts.

The first section of the chapter looks at how the discourse of illness as work is connected to the rise of 'patient work' and a more active sick role. I analyse how this discourse contrasts with other metaphors of illness, such as the metaphor of illness as war or battle. The second section analyses the assumptions and affordances of a set of related metaphors: of illness as career, a goal-oriented progression with

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[6] Carl May, 'The Hard Work of Being Ill', *Chronic Illness*, 2.3 (2006), 161–62 (p. 162). Emphasis in original.

opportunities for advancement, illness as management work, with its connotations of white-collar, middle-class, masculine leadership work, and the representation of the chronically ill person as an ‘entrepreneur’ or ‘enterprise’. I argue that these metaphors allow those who are chronically ill to claim a position within a framework of value from which they are often excluded: the neoliberal worker-citizen. Legibility through this framework also means having political agency. In the third, section, I turn to metaphors of the ill person as a precarious worker. I argue that these metaphors facilitate a broader critique of how capitalism is supported through the designating of ‘surplus’ populations and offer a means through which to break with the binary between worker and surplus. In the fourth section, I look at how the metaphor of the chronically ill person as a precarious worker allows writers to visualise certain affective dimensions of illness, including the sense of development as foreclosed. Moreover, I argue that the figurative language provides access to a history, a register, and a set of forms related to labour struggle which shape the texts.

The work of illness

Illness indisputably *is* work in the sense of ‘action or activity involving physical or mental effort and undertaken in order to achieve a result’ even if I prefer the Arendtian distinction between work (employment) and labour (effort) in this thesis.[7] This distinction, however, is difficult to uphold. How do we categorise tasks that used to be done by medical professionals, but which are now expected to be done by patients? And how do we categorise the tasks that still sit firmly within a doctor or nurse’s formal responsibilities, but which ill people are sometimes forced to

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[7] ‘Work, n.’, *OED Online* (Oxford University Press) <http://www.oed.com/view/Entry/230216> [accessed 21 February 2023]. Definition 4a.

undertake due to medical neglect, such as doing research to correct a wrong diagnosis? The time, effort, and skill expended would still be understood as labour, but this does not fully describe how close the activity is to work. Leigh Claire La Berge writes about *decommodified labour* as 'labour that fails to return a wage even though it requires expending energies and affects in a scene indistinguishable from formal employment'.[8] This term gets closer to describing the fact that much of the labour undertaken by patients overlaps with that done by healthcare professionals.

The increase in patient work can be seen against a backdrop of neoliberal ideology, implemented in the US and UK from the 1970s onwards When the sociologist Talcott Parsons first theorised the 'sick role' in the US in the 1940s and '50s, he described sickness as a temporary role negotiated between the ill person and society, according to which the ill person would be exempt from their normal duties in return for behaving in a specific way.[9] This entailed entrusting the medical establishment with their care, following medical advice, and submitting to treatment. As such, the sick role was a role of 'sanctioned deviance,' policed by the medical establishment with the aim of keeping the workforce healthy, returning all who could to work, and legitimising those who were rightfully excused.[10] However, Anthony Giddens has demonstrated that neoliberal economic policies have overseen the displacement of the responsibility of care from the state or companies to worker citizens themselves.[11] His term for this is *responsibilization*, under which worker citizens are seen as in control of the majority of their risk factors and therefore also largely responsible when they become ill.

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[8] La Berge, p. 26.
[9] Parsons.
[10] Parsons.
[11] Anthony Giddens, *The Consequences of Modernity*, Reprint (Cambridge: Polity Press, 2008).

This is particularly the case in many chronic conditions, which are increasingly managed through home-monitoring technologies and self-administered treatments. People who are ill are now, under normal circumstances, given access to information about their condition, allowed to make decisions about their own treatment, and given the means (technology, sufficient medication, etc) to manage their symptoms from day to day.[12] However, the labour entailed by illness can be difficult and time-consuming, and it is important to note that delegating work to patients and their support networks is often a way of saving costs (in a public healthcare system) or increasing profits (in a privatised system).[13] A more 'proactive' and 'empowered' patient role is cheaper for the system, but it is also a more demanding one for patients; higher expectations of patients and their support systems can exacerbate social inequality.[14] Some people have the means, support, time, and money to take an active role in managing their illness, as well as being able to check on their healthcare providers when necessary, getting second opinions and suggesting new treatments. Others, typically those who are already

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[12] This is also reflected in contemporary artworks. The access to medical data which is now the norm, and what it shows and does not show, is thematised in e.g., Darian Goldin Stahl's artists book *EncodingDecoding* (2016) put together using MRI scans and other medical data. Likewise, living in relation to daily illness management is explored by e.g., Martin O'Brien whose performance pieces such as 'Mucus factory' (2011) and 'It's Good to Breathe In (This Devon Air)' (2015) feature physiotherapy exercises and the beating of the chest to release mucus, motions required of cystic fibrosis patients. By putting these ordinary yet invasive and personal rituals on public display, O'Brien looks at the circular temporality of 'chronic' time and how the needs of an ill body can clash with normative expectations of productivity.

[13] See also Eva Illouz, *Cold Intimacies: The Making of Emotional Capitalism* (Cambridge: Polity, 2007); Olivia Banner, *Communicative Biocapitalism: The Voice of the Patient in Digital Health and the Health Humanities* (Ann Arbor, MI: University of Michigan Press, 2017) <https://www.press.umich.edu/6242145/communicative_biocapitalism> [accessed 18 March 2020]; Michael Staub, *Madness Is Civilization: When the Diagnosis Was Social, 1948-1980* (Chicago, IL: University of Chicago Press, 2011).

[14] While researchers and commentators generally see the overall development as positive for patients, some critics argue that healthcare providers have benefited more than patients and that increased expectations of patients have intensified the effects of inequality. See e.g. Peter Salmon and George M Hall, 'Patient Empowerment or the Emperor's New Clothes', *Journal of the Royal Society of Medicine*, 97.2 (2004), 53–56; Collette Sosnowy, 'Practicing Patienthood Online: Social Media, Chronic Illness, and Lay Expertise', *Societies*, 4.2 (2014), 316–29 <https://doi.org/10.3390/soc4020316>..

disenfranchised or multiply marginalised, do not have the means to do this and therefore end up with worse outcomes.[15]

Social scientists most often describe the labour entailed by illness as ‘patient work’ or ‘the burden of treatment’.[16] Patient work is defined as the ‘exertion of effort and investment of time on the part of patients or family members to produce or accomplish something’ in relation to the illness.[17] As this formulation shows, the labour of patients’ care networks are often, when applicable, included when studying patient work. Sometimes, the work of patients, their care networks, their healthcare providers, and the technologies they use are combined into a ‘patient work system’.[18] Patient work is ‘pervasive’ psychologically and geospatially; it takes place in sites including the home, communities, clinical settings, and places of work.[19] The researchers who term it patient work argue that recognising it *as work* allow for the improvement of these practices, for example through the new field of ‘patient work ergonomics’.[20]

Contemporary illness writing often includes the labour required to navigate medical systems and clinical encounters. As the manifesto for *The Deaf Poets Society*, an online literary magazine for ill and disabled writers, proclaims:

> We are the literature of a people who understands the difficulty of managing physical pain. Of a people who spend days in the white rooms of hospitals, in the

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[15] Salmon and Hall.

[16] Strauss and others; Viet-Thi Tran and others, ‘Taxonomy of the Burden of Treatment: A Multi-Country Web-Based Qualitative Study of Patients with Chronic Conditions’, *BMC Medicine*, 13.1 (2015), 115 <https://doi.org/10.1186/s12916-015-0356-x>.

[17] Anselm Leonard Strauss, *Continual Permutations of Action* (New York: Transaction Publishers, 1993), pp. 64–65.

[18] Richard J. Holden, Christiane C. Schubert, and Robin S. Mickelson, ‘The Patient Work System: An Analysis of Self-Care Performance Barriers among Elderly Heart Failure Patients and Their Informal Caregivers’, *Applied Ergonomics*, 0 (2015), 133–50 <https://doi.org/10.1016/j.apergo.2014.09.009>.

[19] Nan Ye and Richard J. Holden, ‘Exploring the Context of Chronic Illness Self-Care Using Geospatial Analyses’, *Proceedings of the International Symposium on Human Factors and Ergonomics in Health Care*, 4.1 (2015), 37–41 (p. 37).

[20] *The Patient Factor: Theories and Methods for Patient Ergonomics*, ed. by Richard J. Holden Valdez Rupa S. (Boca Raton: CRC Press, 2021).

> labyrinth of referrals and insurance company touchscreen menus that would dizzy Kafka. We are the literature of the recovery rooms, the psych ward, the hospice.[21]

By highlighting these spaces and the effort and skill that goes into navigating them, the magazine acknowledges the importance of these tasks to illness and disability writing. Contemporary illness writers are often deliberate about describing this labour because it is not only often invisible but also gendered. As Boyer describes, the reproductive labour of illness is so much part of the everyday that outsiders may not see it: ‘The background that appears effortless appears only with great effort: the work of care and the work of data are quiet, daily, persistent, and never done’.[22] As with so much other reproductive labour, it is disproportionally undertaken by women. Even female patients are put to work in a way the male patients are not, the narrator observes; in the waiting room, ‘wives fill out their husbands’ forms. Mothers fill out their children’s. Sick women fill out their own’.[23] The administrative and management labour of illness is mundane, but can be skilful, time-consuming, and plays a large part in shaping the contemporary experience of illness.

Whereas an earlier generation of theorists analysed patient labour from the point of view of clinicians, for whom it registered primarily as *compliance* with medical authority, more recent studies focus on the impact of this on those who are ill.[24] As sociolinguist and writer Jan Grue points out, the ill person may be asked anything from how they hold their bodies to how they organise their life:

> Countless micro-interactions between patients and health professionals require patients to move or position their bodies in certain ways, to respond to questions or otherwise provide information, to cooperate with health professionals who have tasks to complete. But patients with chronic illnesses are also responsible for

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[21] The Deaf Poets Society, ‘THE DEAF POETS SOCIETY MANIFESTO’, *Medium*, 2016 <https://medium.com/anomalyblog/the-deaf-poets-society-manifesto-8ded0a3017ab> [accessed 16 July 2020].

[22] Boyer, *The Undying*, pp. 54–55.

[23] Boyer, p. 51.

[24] Strauss and others.

> monitoring their condition, initiating contact with health professionals, following up when appointments are rescheduled or delayed, that is, performing administrative work in tandem with the health bureaucracies and professionals that they depend upon. “Compliance” does not accurately describe these efforts, because they require patients to maintain vigilance and exert agency.[25]

Grue argues that a more active language of illness, such as the use of the metaphor of illness as work, reflects the active sick role and the increased demands on those who are ill. Describing illness as work is a way for patients to emphasise their own agency and the skill that is required to navigate being ill. Grue finds it to be a generative metaphor, especially for those with conditions that are medically contested, have a low degree of social recognition or low medical ‘prestige’—categories that include most mental and chronic illnesses.[26]

The use of metaphors is one of the most studied aspects of illness writing. Anne Hunsaker Hawkins and Arthur Frank describe common typologies and metaphors for illness including the journey, shipwreck, rebirth, quest, restitution, triumph, and chaos.[27] More recent linguistics and digital humanities studies have added metaphors of imprisonment, violence, and burden.[28] Critics have demonstrated how illness writers often structure their text using tropes and plots borrowed from other genres such as adventure stories, fairy tale, conversion stories, or redemption stories.[29] The most discussed metaphor in illness writing and discourse surrounding illness is the metaphor of illness as battle or war. The critique

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[25] Jan Grue, ‘ILLNESS IS WORK: Revisiting the Concept of Illness Careers and Recognizing the Identity Work of Patients with ME/CFS’, *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 20.4 (2016), 1–12 (p. 9).

[26] Grue, p. 3.

[27] Hawkins; Frank; Conway.

[28] Elena Semino and others, ‘The Online Use of Violence and Journey Metaphors by Patients with Cancer, as Compared with Health Professionals: A Mixed Methods Study’, *BMJ Supportive & Palliative Care*, 7.1 (2017), 60–66 <https://doi.org/10.1136/bmjspcare-2014-000785>; Charlotte Hommerberg, Anna Gustafsson, and Anna Sandgren, ‘Battle, Journey, Imprisonment and Burden: Patterns of Metaphor Use in Blogs about Living with Advanced Cancer’, *BMC Palliative Care*, 19 (2020) <https://doi.org/10.1186/s12904-020-00557-6>.

[29] Couser; Hawkins.

of this metaphor was one of the foci of Susan Sontag's *Illness as Metaphor* (1978), in which she argued against metaphoricity in relation to illness. Sontag's critique of the war metaphor has been echoed by many other writers and backed up by psychologists, who have shown that applying battle metaphors to cancer can hurt prevention and treatment measures by making people more fatalistic about cancer outcomes and less likely to seek treatment.[30] Grue writes that in the case of chronic illness, framing illness as a war 'presents the patient as well as the doctors with a battle that cannot be won and a fight that never ends'.[31] In comparison, Grue finds that the metaphor of illness as work 'foregrounds the dynamic and temporal aspects of the illness experience' and can help legitimise the chronically ill person in the eyes of society by highlighting the effort they go through to manage their conditions. However, Anita Wohlmann argues that there is no such thing as a bad metaphor, and that the battle or war metaphor can be empowering when used deliberately as an energizing concept.[32]

The metaphor of illness as work has seen a recent resurgence in both activist chronic illness discourse and literary writing about illness. It is not new; as Sontag describes in *Illness as Metaphor*, the related metaphorical language of economics preceded that of war or battle in the nineteenth century. Although the metaphor can be traced back further—in *The Undying,* Anne Boyer considers illness-motivated pilgrimages and religious prayer houses for the ill as ways to make illness full-time jobs—Sontag focuses on how the language of economics dominated descriptions of illness at the height of the Industrial Revolution. In the nineteenth century and into

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[30] David J. Hauser and Norbert Schwarz, 'The War on Prevention II: Battle Metaphors Undermine Cancer Treatment and Prevention and Do Not Increase Vigilance', *Health Communication*, 2019, 1–7 <https://doi.org/10.1080/10410236.2019.1663465>.

[31] Grue, p. 6.

[32] Anita Wohlmann, *Metaphor in Illness Writing: Fight and Battle Reused* (Edinburgh: Edinburgh University Press, 2022).

the early twentieth century, she argues, illness was frequently understood in terms of mismanagement of vital energy. This could be either a deficiency of energy, such as in tuberculosis in which the patients 'consumes' herself, 'wastes', and 'squanders' her vitality. But the opposite, a repression of energy, was also frequently deemed the cause of pathology, such as in cancer, seen as the result of unexpressed feelings; a refusal to consume or spend 'normally' resulting in abnormal growth.[33]

Sontag sees these economic metaphors as indicative of an early capitalist anxiety about the lack of or misdirection of energy. 'Early capitalism,' she writes, 'assumes the necessity of regulated spending, saving, accounting, discipline—an economy that depends on the rational limitation of desire'.[34] The economic metaphor of illness thus connects a healthy biological and mental state to healthy consumption. Conversely, it posits over- and under-consumption as pathological. Ideas of bodily and economic health thus have a long history of being ideologically related to each other. This also applies to eugenics and other ideologies in which 'optimisation' (at worst through genocide) of population 'health' is equated to the economical 'health of the nation'.[35]

Metaphor is typically understood as the mapping of one domain of experience on to another. According to cognitive linguists George Lakoff and Mark Johnson, 'the essence of metaphor is understanding and experiencing one kind of thing in terms of another'.[36] Lakoff and Johnson use the terminology of 'target' and 'source' domains. 'In a *metaphor*,' they write, 'there are two different domains: the target domain, which is constituted by the immediate subject matter, and the source

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[33] Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), p. 63.
[34] Sontag, *Illness as Metaphor*, p. 63.
[35] Anne-Emanuelle Birn and Natalia Molina, 'In the Name of Public Health', *American Journal of Public Health*, 95.7 (2005), 1095–97 <https://doi.org/10.2105/AJPH.2004.058065>.
[36] George Lakoff and Mark Johnson, *Metaphors We Live By* (Chicago: University of Chicago Press, 2003), p. 5.

domain, in which important metaphorical reasoning takes place and that provides the source concepts used in that reasoning'.[37] In the metaphor of illness as work, the experience of illness is understood and communicated via the source domain of work.[38]

Work grants social legitimacy; as described extensively starting with Max Weber's *The Protestant Ethic and the Spirit of Capitalism* (1905), under capitalism hard work and individual productivity have been placed at the core of what it means to be a good person and citizen.[39] Due to the moral weight carried by the concept of work, it is not surprising that chronically ill and disabled subjects use it to assert their value in the face of discrimination, marginalization, and the continued erosion of social security. As Greg Goldberg has described in relation to digital technology, work has become shorthand for any activity or institution that maintains responsible relationality and sociality.[40] As a heavily loaded term, used about an ever-increasing field of activity (including concepts like reproductive labour, emotional labour, the second shift), work has an expanding denotation. But this also questions the degree to which 'work' is used metaphorically. Asserting that something is work is often a statement about the quality, value, or affective experience of a particular activity, rather than a metaphor. Stating that illness is work can be a political claim for legitimacy as well as be a factual claim about the amount of labour entailed by illness. The metaphor of illness as work is always pushing at the literal; at the opposite end of the spectrum to, for example, the conceits of metaphysical poetry which delight by surprising the reader with far-fetched comparisons, the metaphor of

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[37] Lakoff and Johnson, p. 265.

[38] Lakoff and Johnson, p. 112.

[39] François Guéry and Didier Deleule, *The Productive Body*, translated and introduced by Philip Barnard and Stephen Shapiro (Croydon: Zero Books, 2014).

[40] Greg Goldberg, *Antisocial Media: Anxious Labor in the Digital Economy* (New York: University Press, 2017).

illness as work is always at the point of collapse as the target and source domains overlap and intertwine.

Elaine Scarry argues that the proximity of physical suffering and work in figurative language indicates historical conditions of alienation. Surveying the metaphor of work as suffering in nineteenth and twentieth-century rhetoric, she argues that 'historical moments when work has been identified with suffering have been moments in which those persons performing the activity of work have been separated from the benefits of the objects that are the product of that activity'.[41] Scarry is interested in the reverse metaphor to illness-as-work; however, it is worth noting that the ubiquity of the illness-as-work metaphor goes hand-in-hand with the rise of alienated, precarious, zero-hour work from the early 2000s onwards. This suggests that it is not work in the abstract that resembles illness, but rather that it is specific contemporary configurations of work which writers find useful to express the experience of illness. As Amelia Horgan writes, 'When something is described as "work", a set of claims are made not just about that activity but about "work" too'.[42] It seems that the repetitive, physically demanding, steadily erosive, non-teleological, and potentially painful qualities of much precarious work at this moment converge with the experience of chronic illness.

The tension between doing away with stigma by recasting illness using a high-prestige concept like work and challenging the underlying assumption that working hard carries moral value is something that Lazard returns to in their essays and video installations. In the essay 'How to Be a Person in the Age of Autoimmunity' (2013), Lazard reflects on why the concept of work feels

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[41] Elaine Scarry, *The Body in Pain: The Making and Unmaking of the World* (Oxford: Oxford University Press, 1987), pp. 169–70.
[42] Amelia Horgan, *Lost in Work: Escaping Capitalism* (London: Pluto Press, 2021), p. 48.

indispensable when describing living with the chronic inflammatory illness ankylosing spondylitis. Lazard recognises that telling people around them that taking care of themself is equivalent to full-time employment is a concession to capitalist ideology, but also indicates that the metaphor is testimony to more than just that. Lazard reluctantly acknowledges the similarities between the daily realities of work and illness, with their tedium and routine. 'If I was not seeing a specialist, getting medical tests, or in physical therapy,' Lazard writes, 'I spent most of my time on the Internet, probably as bored as you were at work'.[43]

In this comparison, illness is related to work based on a shared affective experience of boredom and lack of meaning and progress. The comparison also points to the similarity of work and leisure when both are spent on the computer. As Jodi Dean has described, browsing the internet means creating data which can then be sold for profit and used to re-target the user, meaning that many people spend their time off still creating profit for large corporations.[44] Dean uses the term *communicative capitalism* to describe how these circulating data streams have become the basis for capitalist production, arguing that 'paid, unpaid and precarious labor should not be treated separately', since—citing Enda Brophy and Greig de Peuter—these all add up to a 'circuit of exploitation'.[45] Stressing the continuity of unpaid and paid work, as Lazard also does in their comparison, emphasises the similar affective and material effects of these otherwise opposed activities/states.

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[43] Carolyn Lazard, 'How to Be a Person in the Age of Autoimmunity', *Cluster Magazine*, 2013 <https://static1.squarespace.com/static/55c40d69e4b0a45eb985d566/t/58cebc9dc534a59fbdbf98c2/1489943709737/HowtobeaPersonintheAgeofAutoimmunity+%281%29.pdf> [accessed 26 September 2019].

[44] Jodi Dean, 'Communicative Capitalism: Circulation and the Foreclosure of Politics', *Cultural Politics*, 1.1 (2005), 51–74.

[45] Jodi Dean, 'Communicative Capitalism and Class Struggle', *Espheres*, 2014 <https://spheres-journal.org/contribution/communicative-capitalism-and-class-struggle/> [accessed 12 March 2023]; Enda Brophy and Greig de Peuter, 'Labours of Mobility: Communicative Capitalism and the Smartphone Cybertariat', in *Theories of the Mobile Internet: Materialities and Imaginaries*, ed. by Andrew Herman, Jan Hadlaw, and Tom Swiss (London: Routledge, 2014).

Like Wang, Lazard desires a viable alternative to the framework that equates productivity with moral virtue, but despite trying to tap into a sense of an ‘ebb and flow’ as opposed to linear ‘capitalist time designations,’ Lazard continues to fall back on a register associated with work, saying that their desired way of ‘leaning in’ to illness should allow them to ‘refuse to overbook [them]self’ while at the same time ‘diligently’ managing their time and taking their medications.[46] The language of ‘leaning in’ references Sheryl Sandberg’s bestselling self-help book *Lean In: Women, Work and the Will to Lead* (2013), published earlier the same year. In her book, Sandberg argues that workplace inequality is caused by both external and internal barriers, which can be partially addressed by women being more aggressive in their careers and setting clear boundaries. In Lazard’s essay, managing illness becomes similarly individual, even if Lazard understands the problems structurally.

The metaphor of chronic illness as work thus serves a number of different purposes. It can be a way for those with chronic illness to claim legitimacy through a language which is already valued by society. Describing illness as work or a job is also a way of drawing attention to the fact that illness, and especially chronic illness, in fact entails a high amount of administrative and reproductive labour. This is not something new; the word *administration* comes from the world of care and illness, with the Oxford English Dictionary citing its etymology in the ‘action of taking care, looking after’.[47] This sense survives in the phrase *ministering to the sick* and in administration as the verb for dispensing drugs or treatments. To *minister* is to tend to. But with the responsibilization of worker-citizens and the proactive sick role, those who are chronically ill are increasingly expected to undertake this labour

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[46] Lazard, ‘How to Be a Person in the Age of Autoimmunity’.
[47] ‘Administration, n.’, *OED Online* (Oxford University Press) <http://www.oed.com/view/Entry/2541> [accessed 12 February 2023].

themselves. Being chronically ill does not mean being on bed rest (all the time, anyway); it very often means waiting in hospitals, undertaking detailed monitoring, filling out complicated forms, attending and administrating treatments, and the daily labour of finding accommodations and making life work around fluctuating symptoms and capacities. The metaphor, however, can also indicate certain affective similarities between illness and work: boredom, repetitiveness, exhaustion.

lllness both is and is not work, depending on the specific sense in which work is understood. Describing illness as work can be synecdoche, a form of figurative language in which a part of something is substituted for the whole. But being ill has many aspects to it; it is notable that in contemporary illness writing, it is the work entailed by illness that so often comes to stand for the whole. This indicates that having to expend energy and undertake new tasks and responsibilities is a significant aspect of the contemporary experience of illness. Although illness entails a lot of work, illness is not literally a full-time job, however. This recalls Julia Bryan-Wilson's description of what she calls *occupational realism*, artworks in which artists take a role as a worker, for example by taking a job that pays better and more regularly than being an artist. Bryan-Wilson suggests that the tension set up and explored by the artworks employing this mechanism derives from the fact that artist exploit the similarity but ultimate non-commensurability of two activities. This, she argues, is

> precisely what makes occupational realism legible as a form of practice—there is a gap between these non-identical categories wide enough that their bridging feels surprising. If art were already work, or work were already art, these projects that redefine art as work and vice versa would simply fail to register as inversions, as conceptual frames, or as critiques.[48]

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[48] Julia Bryan-Wilson, 'Occupational Realism', in *It's the Political Economy, Stupid: The Global Financial Crisis in Art and Theory*, ed. by Gregory Sholette and Oliver Ressler (Pluto Press, 2013), pp. 84–93 (p. 91).

The gap between ill person and worker is there, even if illness entails labour. This tension animates the texts; there is still something at stake in claiming that illness is work, even if it *almost* and sometimes is.

Due to the diffusiveness of the metaphor of illness as work, the rest of this chapter focuses on literary examples in which the comparison between illness and work is taken one step further into figurative language, describing illness as a job or career, or by extending the metaphor so that more aspects than usual from the source domain of work is mapped on to illness. The metaphors considered are illness as a full-time job; as management; as career; the ill person as entrepreneur or enterprise; illness as unpaid work; and as precarious work. I will then consider the counter-discourses of illness as strike and illness writing as unionising which follow from the figuration of ill people as precarious workers.

Illness careers

Using a source domain of professional ambition to describe living with chronic illness is not a new phenomenon in illness writing. Alice James, sister of William and Henry James, is an apt case study, as her diaries have been the centre of a debate about the configuration of illness as a career. She described her own desire for a diagnosis as an 'aspiration'; at finally receiving a breast cancer diagnosis in 1891, she wrote in her diary: 'To him who waits, all things come! My aspirations may have been eccentric, but I cannot complain now, that they have not been brilliantly fulfilled'.[49] She also describes the discomforts of arranging herself and describes

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[49] Alice James, *The Diary of Alice James*, ed. by Leon Edel (Dodd, Mead & Company, 1964), pp. 206–7. May 31st, 1891.

small setbacks as 'all in the day's work for an invalid'.[50] Her diaries display a constant preoccupation with defining her own worth outside of either a career or having a family. 'Though I have no productive worth,' she writes, 'I have a certain value as an indestructible quantity'.[51] Living at a time when it was not deemed respectable for a middle-class woman to have a career, critics have compared the life she had to what she might have accomplished had she been able to pursue a career and her education further, essentially seeing James' illness as resulting from being curbed intellectually. Elizabeth Bronfen writes that James's 'nervous ailment was intimately connected both with the feminine role her culture ascribed to her and with her resistance to the lethal boredom of enforced uselessness, the stifling of her active nature, the frustration of her youthful hopes that went along with being a young woman in mid-nineteenth-century New England'.[52] James' biographer Jean Strouse is explicit in his argument, describing how James's 'miserable health *was* her career' and writing that 'the intelligence and energy Alice might have used in some productive way went into the intricate work of being sick'.[53] With the amount of commentators describing her illness specifically as a 'career', the phrase has been closely attached to her.[54] Some critics have argued that James' use of economic language is a way to make herself legible, with Natalie Dykstra writing that it was a way of 'using the lingua franca of value production in the nineteenth century: the

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[50] James, *The Diary of Alice James*, p. 66.
[51] James, *The Diary of Alice James*, p. 207.
[52] Elisabeth Bronfen, 'Case Study. Henry's Sister—Alice James (1848-92).', in *Over Her Dead Body: Death, Femininity, and the Aesthetic* (New York: Routledge, 1992), p. 385.
[53] Jean Strouse, *Alice James: A Biography* (Boston: Houghton Mifflin, 1980), p. 291.
[54] Katherine Winton Evans, 'Alice James: Sister of Genius', *Washington Post*, 30 November 1980 <https://www.washingtonpost.com/archive/entertainment/books/1980/11/30/alice-james-sister-of-genius/50d70c3c-07fd-4e11-97b0-66259c9e4041/> [accessed 6 April 2023]; Margo Culley, *American Women's Autobiography: Fea(s)Ts of Memory* (Univ of Wisconsin Press, 1992), p. 149; Alice James, *The Death and Letters of Alice James: Selected Correspondence*, ed. by Ruth Yeazell (Exact Change, 2004).

nouns and verbs of capitalism and industry.[55] Shawna Rushford-Spence describes the subversiveness of this act: 'While the privilege of acting as a productive citizen was historically reserved for the able-bodied rather than the disabled, James employs the commonplaces of neurasthenic discourse—notions of bodily energy, force, spending, and waste— to resist the ways in which the dominant culture classified women with disabilities as in-valid, thereby situating herself as socially and culturally viable'.[56] While Dystra argues that James reframes the whole experience of illness as 'work', Rushford-Spence sees the concept of work as very specifically attached to the task of 'managing pain'.[57]

Susan Sontag's play *Alice in Bed* (1991) is also a response to the theme of frustrated ambitions in James' writing and a meditation on the relation between structural oppression and pathology. In the afterword, Sontag describes Alice as an example of 'the all too common reality of a woman who does not know what to do with her genius, her originality, her aggressiveness, and therefore becomes a career invalid'.[58] Sontag references Virginia Woolf's thought experiment on what would have happened had Shakespeare had an equally brilliant sister, speculating that she would have remained silent, 'not merely for want of encouragement', but

> Silent because of the way women are defined and therefore, commonly, define themselves. For the obligation to be physically attractive and patient and nurturing and docile and sensitive and deferential to fathers (to brothers, to husbands) contradicts and *must* collide with the egocentricity and aggressiveness and the indifference to self that a large creative gift requires in order to flourish.[59]

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[55] Natalie A. Dykstra, '"Trying to Idle": Work and Disability in The Diary of Alice James', in *The New Disability History: American Perspectives*, ed. by Paul K. Longmore and Lauri Umanksi (New York: New York University Press, 2001), p. 122.

[56] Shawna Rushford-Spence, '"How Well One Has to Be, to Be Ill!": Work, Pain, and the Discourse of Neurasthenia in The Diary of Alice James', *Disability Studies Quarterly*, 34.3 (2014) <https://doi.org/10.18061/dsq.v34i3.3917>.

[57] Rushford-Spence.

[58] Susan Sontag, *Alice in Bed: A Play* (New York: Farrar, Straus and Giroux, 1993), p. 115.

[59] Sontag, *Alice in Bed*, p. 133. Emphasis in original.

Sontag insists that egocentricity, aggressiveness, and indifference to self are central to successful creative expression, qualities which are positioned as incommensurable with domesticity. Sontag's metaphorical reading of James' illness also marks a development in Sontag's work from *Illness as Metaphor* (1978) in which she explicitly cautions against reading illness metaphorically in this way.

In the play, Alice is often shown with ten or more thin mattresses piled on top of her. With Sontags comment in mind, we may see this as a staged metaphor, the mattresses signify the gendered expectations of emotional and reproductive labour that hold her down and suffocate her under the weight. Throughout the play, the idea of women's labour is expanded, with the character of Alice describing the bind she is in, speaking to her brother, Henry: 'Well I am a woman and that's a woman's job, to comfort and reassure men, even from the bed sickbed deathbed birthbed, to which the man has come, on tiptoe, to visit and comfort, is it not'.[60] The central scene of the play expands the link to Lewis Carroll's *Alice in Wonderland* by featuring a tea party that includes other brilliant women whose 'careers', in various senses, were curtailed: Emily Dickinson, Margaret Fuller, Kundry of Wagner's *Parsifal* and Myrtha, the Queen of the *Wilis*, 'a company of ghosts of young women who, betrayed in love, have died prematurely, from the ballet *Giselle*.[61]

It is a tea party where no one has made tea because no one wants to. As the character of Margaret Fuller exclaims: 'there isn't any [tea] and I shouldn't have offered because I am not and do not want to be the hostess'.[62] Alice and Margaret decide to smoke opium instead, which is brought to them by the characters MI and MII—Man I and Man II?—who are Brechtian stage hands, continually changing the

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[60] Sontag, *Alice in Bed*, p. 40.
[61] Sontag, *Alice in Bed*, p. 116.
[62] Sontag, *Alice in Bed*, p. 48.

scene and being commanded by the female characters. The play thus takes palpable joy in the female characters' refusals of domestic labour. As Alice says: 'We're talking about helplessness. We're invoking revolt'.[63] But this revolt never comes, and Alice goes back to bed. Refusal of reproductive labour does not grant the women entry to the public arenas that would let them develop professional skills or build a livelihood. If the female characters do not want to undertake domestic work and are structurally foreclosed from undertaking professional work, the only remaining option is total passivity.

Stating that illness is work only carries some of the connotations of stating that illness is a full-time job. A full-time job invokes the respectability of fully reaching the threshold of societally mandated productivity. Similarly respectable is the concept of the illness *career.* The concept of 'illness careers' entered medical sociology through Erving Goffman's *Asylums* (1961). Goffman used it as an analytical concept for the 'mental patients' he studied, arguing that considering patients' trajectories as 'careers' allows the researcher 'to move back and forth between the personal and the public, between the self and its significant society, without having to rely overly for data upon what the person says he thinks he imagines himself to be'.[64] From Goffman onwards, the idea of the illness 'career,' while perhaps seemingly contradictory, has been used to generalise the sense of movement through stages that are both individual and systematic, as well as applied to trajectories of health and progression through stages of treatment.

Goffman writes that while one sense of the word denotes goal-oriented and committed progress 'within a respectable profession', 'career' can also mean simple

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[63] Sontag, *Alice in Bed*, p. 75.
[64] Erving Goffman, *Asylums* (Harmondsworth: Penguin Books, 1961), p. 127.

and neutral progression through time, applicable to ‘any social strand of any person’s course through life’.[65] He argues that he only uses this second, neutral sense of ‘career’ in his study. However, the connotation of moral respectability clearly forms part of the term’s usefulness in his analysis. The concept of ‘career’ and particularly its ‘*moral* aspects’ are useful, Goffman argues, for analysing ‘the regular sequence of changes […] in the person’s self and in his framework of imagery for judging himself and others’.[66] The idea of the illness career thus expresses aspects of both identity and self-representation, as well as the willingness to embrace medical terminology and become institutional legible. While medical sociologists from Goffman onwards purport to use ‘career’ simply to express a generalisable trajectory, the concept therefore comes loaded with meanings that have undeniable implications.[67] While most researchers do not see it as an instance of figurative language, I argue that it is in fact useful to see it as such. Seeing ‘illness career’ as an instance of metaphor allows us to consider how this widespread term reflects an increasing ‘professionalisation’ of the patient role that shapes the experience of illness. Moreover, having a career implies not only participating in a trajectory but having a certain status in society.

As Grue has pointed out, a career is a form of ‘goal-directed progression’.[68] Emphasising this dimension in our understanding of illness careers can indicate positive intentionality and possibility for advancement—both dimensions which reflect patients’ sense of their own agency when being ill. Specifically, it can

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[65] Goffman, p. 127.
[66] Goffman, p. 128. Emphasis in original.
[67] See e.g., Bradley J. Fisher, ‘Illness Career Descent in Institutions for the Elderly’, *Qualitative Sociology*, 10.2 (1987), 132–45 (p. 132) <https://doi.org/10.1007/BF00988525>; Bob Price, ‘Illness Careers: The Chronic Illness Experience’, *Journal of Advanced Nursing*, 24.2 (1996), 275–79 <https://doi.org/10.1046/j.1365-2648.1996.02047.x>; Julius Sim and Sue Madden, ‘Illness Experience in Fibromyalgia Syndrome: A Metasynthesis of Qualitative Studies’, *Social Science & Medicine (1982)*, 67.1 (2008), 57–67 <https://doi.org/10.1016/j.socscimed.2008.03.003>.
[68] Grue, p. 2.

represent the institutionally unrecognized work they undertake in achieving diagnosis and participating in advocacy.[69] Building on the work of Lakoff and Johnson, Grue argues that the source domain of professionalism from which 'career' is borrowed can be used to confer meanings of agency, controlled progression, opportunity, and prestige unto illness. This is particularly the case for those who live with chronic, contested, and/or medically 'low-prestige' illnesses, he argues, and for whom the idea of building an 'illness career' can be empowering.

The use of 'career', Grue writes, should be distinguished from the related metaphors of (full-time) job and work/labour. 'If ILLNESS IS WORK […] then an illness career is a possible but not a necessary way to shape one's understanding of that work; in the source domain of WORK, a career is usually distinguished from simply having a job'.[70] This tension forms the central point of this chapter, moving as it does from contemporary illness texts that explore the sense of illness work as 'career'—a field where advancement is possible subject to individual ambition and skill, to the development of a contrasting metaphor: illness as precarious work, in which progression is structurally foreclosed. While the demands of contemporary constructions of patienthood are reflected in both, the metaphor of illness as precarious work has radically different implications, and, I argue, go hand in hand with other efforts in contemporary feminist illness writing to resist teleological progression.

Many of the writers discussed in this thesis can be seen to have created an 'illness career' in a literal sense. They have turned their experiences of illness into texts or other creative outputs that they have sold. Typically, these texts have opened

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[69] Grue, p. 3.
[70] Grue, p. 7.

doors to new work opportunities and audiences, thus contributing to a career, even if creative careers often carry low and unpredictable pay and little job security. Working as a writer is in many ways outside the norms of employment and productivity valued most highly by economists, necessitating the claims to value as described in Chapter 1.[71] We can see this tension in the comparisons set up by illness writers. Wang invokes the qualities of individual agency, controlled progression, and dogged ambition in her description of illness, but also points to negative aspects such as precarity and having to constantly push herself beyond her limits. In Lazard's comparable essay, illness is described as boring and mundane work, comparative to the office temp jobs their friends have in their early twenties. Illness is similarly soul-destroying and boring, even if the worst-paid job still comes with more societal understanding and prestige.

Closely related to the metaphor of illness as work is the concept of *managing* illness. Management can mean either coping in the face of difficulty or being in command of something.[72] While the first usage is so common as to not register its connotations, contemporary illness writing often calls on and extends the second meaning. Disability and chronic illness advocate Alex Haagaard draws heavily on the semantic field related to finance and business to figure illness as a management job in an article for the job site *The Muse*. I have italicised the management-based language in this excerpt:

> Learning to *manage* your *energy levels* is essential when living with chronic illness. You get used to *checking in* with your body, *assessing* how much any activity will *cost* you, and *creating a kind of energy budget* to figure out exactly what you can get done without pushing your body past its breaking point. But what happens when

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[71] On the history of the low social valuation of creative jobs, as well as sectors like childcare, nursing work, domestic labour, teaching and retail, all staffed predominantly by women and people of colour, see e.g., Jaffe.

[72] 'Manage, n.2', *OED Online* (Oxford University Press) <https://www.oed.com/view/Entry/113209> [accessed 6 April 2023].

> there's just no way to *balance the budget*? This is a huge challenge in workplace cultures that *place a premium* on constant *productivity*. Chronically ill employees often end up going into *energy debt* trying to keep up with what's expected of them.[73]

Haagaard's choice of register creates a positive representation of the ill person as an active, capable person who is working hard at managing their own condition, even at the moments when an employer (and by extension, society) may see them as being unproductive. In other words, Haagaard echoes claims such as made in a *Forbes* article arguing that chronic illness 'can make us more determined and adaptable workers' and that managing illness can be a training ground for traditional employment.[74] The article highlights adapting to changing circumstances and resilience as important skills developed by people living with chronic illnesses and presents people with chronic illnesses as an untapped reserve for employers.

This is an argument also echoed in some illness writing, such as in Nasim Marie Jafry's *The State of Me* (2008) in which the chronically ill protagonist writes an imagined Curriculum Vitae that includes 'mystery illness (has taught me a lot), 1983 - present' under the header of 'Education'.[75] Haagaard does something similar by invoking high-status jobs, the verb constructions 'assessing […] cost,' 'balancing the budget', and 'place a premium' recalling jobs within the fields of business, finance, and insurance. The work of managing illness is thus mapped on to professionalism through a metaphor that valorises the value of a specific kind of work: white collar, full-time, leadership, and entrepreneurial work within highly-paid but difficult-to-access sectors. Business and finance jobs are examples of what Marxists call *immaterial labour*, jobs which downplay bodily capability in favour of

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[73] Haagaard. My emphasis.

[74] Manon DeFelice, 'The Surprising Truth About Chronic Illness And The Future Of Work', *Forbes*, 4 September 2019 <https://www.forbes.com/sites/manondefelice/2019/09/04/the-surprising-truth-about-chronic-illness-and-the-future-of-work/#2844edf13e38> [accessed 26 February 2020].

[75] Nasim Marie Jafry, *The State of Me* (London: The Friday Project, 2008), p. 420.

a more abstract sense of proficiency based on the ordering of information and individual expertise. Management work puts aside the body because it is manifestly *not* manual labour. Thus, the metaphor inscribes itself into one of the higher rungs of an already dominant hierarchy among different forms of work. In the US and UK, management jobs are dominated by those who are already privileged, namely white, highly educated, cisgender men from wealthy backgrounds. They often have 'glass ceilings,' seemingly invisible barriers which reduce the access of other demographics beyond a certain level. While the metaphor of illness as a 'management job' has been embraced as more empowering than the metaphor of illness as a type of war, it thus also carries some exclusionary connotations. When someone as marginalised as those who are chronically ill claim these qualities, they invoke the exclusivity and prestige related to the register, but also challenge it through their inclusion.

With metaphors like 'energy budgets,' a comparison is set up between energy and money, with energy figured as a finite resource which can be expended, borrowed, or loaned out. The passage describes the employment relation as one in which the employer is trying to extract as much energy from the employee as possible, while the employee is working to opposite ends, trying to conserve their energy. Except, in the passage, the relation exists doubly: in the actual relation between employer and chronically ill employee and then reproduced within the chronically ill employee's relationship to themself. The chronically ill person is represented through a Cartesian duality that figures the mind as the employer and the body as the employee, the bodymind functioning like a business comprised of both manager and managed. As such, the chronically ill worker becomes a microcosm of the work relation that they exist in difficult relation to. As an article written for a job site, the text is presumably commissioned as a way for the website, and the employers it represents, to show ill and disabled job seekers that they understand their needs. But the metaphor also reverses this relation to suggest to employers that the chronically ill person understand *their* positions. The chronically ill employee is shown to have unique insight into the position of their manager, because the ill employee is already an expert in managing an ill body.

Huber concretises this metaphor in *Pain Woman Stole Your Keys*, providing the image of ill person as simultaneously manager and worker*:*

> When I feel sick and decide I need a rest or, deity forbid, a day on the couch, I have to go hat in hand up to the boss's dingy office at the top of the stairs. Boss-Me apparently needs to inspire fear, needs to look with concern and doubt at Employee-Me's to-do list. Boss-Me sighs and says, 'Okay, take a break, but I want you back up to full capacity tomorrow.' I have been well trained.[76]

The image conjures the labour division of an earlier, industrial age, the masculine-coded worker with the hat off to show humility, ascending the stairs from the factory floor to the overseer's office located to facilitate effective surveillance of the workers. The boss' office is 'dingy', suggesting that the boss is also a worker of a kind, a middle manager who is in turn exploited by capital. In describing being 'well-trained', Huber points to the internalisation of a neoliberal framework of the individual as manager of themselves also described by Wang and Lazard.

An early theorisation of this self-conceptualisation as central to the workings of neoliberal ideology was made by Foucault in his 1979 lectures at the Collège de France, later published as *The Birth of Biopolitics*. Before neoliberalism had entered its dominant phase in the West, often seen to begin with the election of Ronald Reagan in the US and Margaret Thatcher in the UK, Foucault theorised neoliberalism as a particular *conduct of conduct* in which the individual was made to

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[76] Huber, pp. 45–46.

conceive of themselves as an ‘entrepreneur’. Encouraged to understand themselves as a sort of enterprise, *‘Homo œconomicus* is an entrepreneur, an entrepreneur of himself […] being for himself his own capital, being for himself his own producer, being for himself the course of [his] earnings’.[77] The chronically ill person of Huber’s extended metaphor is a *homo œconomicus*, an ‘eminently governable’ subject who has internalised governmentality to see their own labour as a form of ‘capital, that is to say, it is an ability, a skill’, to be invested.[78] This posits themselves ideologically as ‘the source of [their] earnings,’ in effect precisely as their own employer.[79] But the metaphor punctures this, presenting both boss and worker as subjected to those who truly benefit from their work, an external and somewhat invisible third actor.

According to Foucault’s theorisation of the neoliberal individual, chronic illness would be one of the ‘innate elements and other, acquired elements’ that make up human capital.[80] According to this conceptualisation, the chronically ill neoliberal subject is not outside the system of individual entrepreneurs, but rather has an extra challenge in investing scarce resources to the largest possible return. The ill person is expected to fend for themselves as the ideal of the individual who responsibly self-manages and absolves the responsibility of the state, as described by Giddens’ concept of responsibilization. This poses a central problem for conceptualisations of resistance, as Lois McNay points out, asking: ‘If individual autonomy is not the opposite of or limit to neoliberal governance, but rather lies at the heart of disciplinary control through responsible self-management, what are the possible

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[77] Foucault, p. 226.
[78] Michel Foucault, *The Birth of Biopolitics: Lectures at the Collège de France, 1978-1979*, trans. by Graham Burchell, Michel Foucault, Lectures at the Collège de France (London: Palgrave Macmillan, 2008), p. 224 <https://doi.org/10.1057/9780230594180>.
[79] Foucault, p. 226.
[80] Foucault, *The Birth of Biopolitics*, p. 227.

grounds upon which political resistance can be based?'[81] McNay finds that Foucault's own later work on an ethics of the self as a form of resistance falls short according to this earlier analysis in which freedom of individual choice is the very technology through which neoliberal governmentality is enforced. The power of the neoliberal logic is that it is able to absorb all forms of individual resistance.

The passages from Haagard, Wang, and Huber can be read as using the metaphor of responsible self-management in an empowering way to counter stigma and prejudice against those with chronic illness. However, positing the management of illness as an activity that, with the right discipline and skill, holds possibility for advancement, individualises self-care and risk management. As effective as the argument may be when activists are addressing employers or reminding others who are chronically ill of their worth, skills and contributions, it also perpetuates a hierarchy between those who can manage their own conditions and those who cannot. By adopting the frameworks of *work* and *management* as shorthands for value and agency, activists to some extent accept and perpetuate the hegemony of productivity. Anti- and post-work thinkers like Kathi Weeks, Nick Srnicek, and David Frayne have criticized the tendency by which work has become the dominant framework for describing value. As David Frayne observes in *The Refusal of Work*,

> in affluent societies, work is powerfully promoted as the pivot around which identities are properly formed. It is valorised as a medium of personal growth and fulfilment, and constructed as a means of acquiring social recognition and respect. All of this we recognise, even if work's ultimate function is in most cases to generate private profit.[82]

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[81] Lois Mcnay, 'Self as Enterprise: Dilemmas of Control and Resistance in Foucault's The Birth of Biopolitics', *Theory, Culture & Society*, 26.6 (2009), 55–77 (p. 56).

[82] David Frayne, *The Refusal of Work: The Theory and Practice of Resistance to Work* (London: Zed Books, 2015), p. 15.

The fact that even illness and *the inability to keep up with the demands of a job* due to chronic illness can be reframed in the language of employability demonstrates the pervasiveness of this framework.

The tension between claiming individual agency in the face of difficult and often isolated struggle with illness and working for a radically different future in which health is not individualised, can be seen in much contemporary illness writing. The variations of metaphors of illness as work—career and management especially—are at the centre of this tension. Different metaphors of work figure illness in different and complex ways, reflecting the changes to the patient role. But each metaphor also carries different affordances for how political resistance can be imagined. The rest of this chapter looks at how figuring illness as precarious work carries radically different implications and affordances because the emphasis on solidarity de-individualises the struggle, thus breaking the bind of neoliberal logic.

The sick woman as precarious worker

In *The Undying*, Boyer portrays the pressure to perform health and femininity even in illness. She describes how the requirements in illness include medical compliance and patient work but also extend far beyond these. Recalling Audre Lorde's descriptions of being pressured to wear a prosthesis after her mastectomy in *The Cancer Journals*, Boyer chronicles the pressure to perform health and a narrow stereotype of traditional femininity. The expectations of the ill person to 'self-manage' includes large amounts of labour:

> *Self-manage*, the boss that is everyone says: *work harder, stay positive, draw on eyebrows, cover your head with a wig or colorful scarf, insert teardrop- or half-a-globe-shaped silicone under your scarred skin and graft on prosthetic nipples or tattoo trompe-l'oeil ones in pubescent pink or have flaps of fat removed from your back or belly and joined to your chest, exercise when tired, eat when repulsed by*

> *food, go to yoga, do not mention death, take an Ativan, behave normally, think of the future, cooperate with the doctors, attend "look good feel better" for your free high-quality makeup kit, run a 5k, whether-or-not-to-wear-a-wig-during-sex is a question the book says to ask your husband, "one family member at a time" says the sign on the way to the infusion room, the pink ribbon on the for-sale sign of the mansion*.[83]

The list connects the pressure to perform outward health with the demand to 'work harder,' emphasising the link between seeming health and productivity. The pressures to conform to a specific cheery image of health–what Barbara Ehrenreich describes as the 'tyranny of positive thinking' prevalent in breast cancer culture—is cemented through consumption of make-up, wigs, and clothing.[84] By positing these cultural expectations as being issued from a 'boss that is everyone', she figures the ill woman as a worker on the receiving end of a set of orders that are impossible to fulfil; the lowest member of the societal hierarchy. The narrator conversely describes the benefactor of the 'boss that is everyone' (i.e., internalised capitalist ideology) as '*the white supremacist capitalist patriarchy ruinous carcinogenosphere*'.[85]

This analogy is also echoed in Boyer's 'Woman Sitting at the Machine', analysed in the Introduction, in which the narrator concludes that:

> Cancer may not be work, but it *feels* enough like it that it is no longer necessary to search for its exact category. It is enough to know that our cancers make the rich richer and so does our debt. Our work, both paid and unpaid, does that too.[86]

While the affective register of how cancer 'feels' can contain some of what the economic register cannot, she remains unable to escape the economic categories of work, debt, and profit; illness continues to be inextricably bound up with capitalism, emotionally as well as financially. The 'work' that cancer '*feels* enough like' is work that—paid or unpaid—'make the rich richer', that is, exploitative, and as suggested

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[83] Boyer, p. 73. Emphasis in original.

[84] Barbara Ehrenreich, *Smile or Die: How Positive Thinking Fooled American and the World* (London: Granta, 2009), p. 42.

[85] Boyer, p. 78. Emphasis in original.

[86] Boyer, *A Handbook of Disappointed Fate*, p. 177.

by the unpaid dimension, gendered work. The types of work that are referenced throughout the essay are precarious, manual, or low-paid. Boyer references lessons learned from her friend's summer job in road construction, as well as the poet Karen Brodine's work in typesetting, waiting tables, and working as a clerk. The remainders of the body the narrator cannot make fit with economic classification are compared to these jobs. 'I'm thinking but not thinking very clearly,' the narrator writes,

> can't tell if a profitable illness is a type of work or a type of commodity or some other economic classification. I look for the proper economic term for a body as a sinkhole as a war wound as a poisoned animal as the saddest, most cut-open thing to ever exist.[87]

The metaphor of 'a body as a sinkhole' mirrors the mention of road construction while the metaphor of illness as a 'war wound' also references the high-risk and in the US also often lower social class military work. The body as 'poisoned animal' and cancer as a 'work injury' (a metaphor used elsewhere in the essay) reflects the description of the dangerous chemicals involved in typesetting, pointing out the ways in which cancer can be related to the workplace.

Going back to Scarry's observation that the proximity of physical suffering and work in figurative language indicates historical conditions of alienation, the illness Boyer describes is related to the conditions of the types of labour she invokes. Her cancer is proposed to be a result of carrying her phone on her chest, a possible 'souvenir' of having to 'always be at work'.[88] The metaphor of illness as precarious work has very different implications than those of illness as career, management work, and the ill person as enterprise. Precarious work is defined as 'work that is *uncertain*, *unstable*, and *insecure* and in which *employees bear the risks of work* (as

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[87] Boyer, *A Handbook of Disappointed Fate*, pp. 175–76.
[88] Boyer, *A Handbook of Disappointed Fate*, p. 177.

opposed to businesses or the government) and *receive limited social benefits and statutory protections*'.[89] It is work without the possibility of advancement; work where progression into less strenuous tasks and higher remuneration is foreclosed. Although zero-hour contracts and other gig economy jobs are often sold as work with a high degree of autonomy (the worker as enterprise), the precarious worker in reality has little to no control over the conditions of their work.[90]

Boyer's essay is a partial rewriting of Karen Brodine's poetry collection *Woman Sitting at the Machine, Thinking* (1978). In Boyer's essay, Brodine's poetry represents a time before the total collapse of work into all other realms of life, when 'work in the U.S.' had only just begun 'seeping out of its forty hour container, spreading onto everything,' and when political resistance still seemed possible.[91] Brodine was writing when 'people could still get full-time jobs' and 'the moment that interrupted poetry was from 9 to 5'.[92] Even at work, there was a limit to which parts of themselves the workers sold, the narrator notes. She cites Brodine: 'our hands mainly / and our backs. and chunks of our brains. and veiled expressions / on our faces, they buy. though they can't know what actual / thoughts stand behind our eyes'.[93] In the factory-like settings described by Brodine, there is a clear separation between management 'barricaded behind their desks' and the workers, who maintain solidarity with each other through shared ideas. In the essay, Boyer's narrator describes Brodine's collection as a text that

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[89] 'Probing Precarious Work: Theory, Research, and Politics', ed. by Arne L. Kalleberg and Steven P. Vallas, *Research in the Sociology of Work*, 31.1 (2017), 1–30 (p. 1). Emphasis in original.

[90] Kalleberg and Vallas. For an example of the argument that the gig and platform economies offers new forms of agency for the enterprising individual, see Richard Florida, *The Rise of the Creative Class* (New York: Basic Books, 2019).

[91] Boyer, *A Handbook of Disappointed Fate*, p. 173.

[92] Boyer, *A Handbook of Disappointed Fate*, p. 173.

[93] Boyer, *A Handbook of Disappointed Fate*, p. 175.

> is about what work takes from workers, but also about what it can't take: intelligence, resistance, solidarity, action on the street, and dreams like 'the buildings around us are plastered with hundreds of / red stickers that shout STRIKE STRIKE STRIKE.'[94]

There is wistfulness in this characterisation of class solidarity and separation of labour and ideas. Boyer borrows Brodine's title, *Woman Sitting at the Machine, Thinking,* for her essay, but omits the last word, suggesting that contemporary types of work no longer allow space to think in ways that are beyond the control of employers or capital more generally.

Boyer's narrator describes her own present as one in which work is precarious but inescapable: 'It's like how everyone I know who doesn't have a job needs one, and everyone who has a job needs to take the red exit out of there'.[95] This recalls Michael Denning's wry observation that 'under capitalism, the only thing worse than being exploited is not being exploited'.[96] However, the dream of strike borrowed from Brodine's text is also generative. Boyer's engagement with Brodine's collection about the exploitative realities of work and the utopian longings of labour activism implicitly suggests an answer to the question she is struggling with. If illness is analogous to precarious work, what can labour activism teach us about improving conditions for the illness workers? Like Lazard and Wang, Boyer's narrator is unable to find a way of speaking about the body that is independent of the framework of work. But rather than seeing that as a failure, she looks for ways to resist the paradigm of work by using the affordances of work's own cultural historical framework. In *The Undying*, this becomes the idea of illness as a form of strike and of illness as the entry point to a shared, historical condition of exhaustion,

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[94] Boyer, *A Handbook of Disappointed Fate*, p. 173.
[95] Boyer, *A Handbook of Disappointed Fate*, p. 175.
[96] Denning, p. 79.

‘a once-proletarian feeling [that] has now become a feeling of the proletarianized all’.[97] The sick woman comes to stand in for the condition of always falling short of capitalist ideals. Embracing the condition of illness, and seeing it as structural and proletarian, posits it as a political position, from which revolt and change can be organised.

In this, Boyer builds on Johanna Hedva’s influential ‘Sick Woman Theory’ (2016). Within literary criticism, the essay’s manifesto-like qualities have been seen as emblematic of a new generation of feminist autobiographical writing, with one critic arguing that the text ‘crystallizes [...] a newly urgent nexus of auto/biographical production, scholarship, and activism’ and another arguing that ‘Sick Woman Theory’ is engaged in developing nothing less than ‘a counterpractice for twenty-first century feminist life—as another way of understanding feminist agency, or what it means to be an activist, an artist, or a theorist’.[98] In the essay, Hedva also uses illness as a result and emblem of manufactured inequality, exploiting the affinity between illness and precarious work. In bed, unable to join the Black Lives Matter protests of 2014, Hedva’s narrator describes reflecting:

> I started to think about what modes of protest are afforded to sick people—it seemed to me that many for whom Black Lives Matter is especially in service, might not be able to be present for the marches because they were imprisoned by a job, the threat of being fired from their job if they marched, or literal incarceration, and of course the threat of violence and police brutality—but also because of illness or disability, or because they were caring for someone with an illness or disability.[99]

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[97] Boyer, *The Undying*, p. 246.

[98] Sarah Brophy, ‘Introduction: Mediated Embodiments | Embodied Meditations’, *a/b: Auto/Biography Studies*, 33:2 (2018), 267-278, p. 268; Lauren Fournier, 'Sick Women, Sad Girls, and Selfie Theory: Autotheory as Contemporary Feminist Practice', *a|b: AUTO|BIOGRAPHY STUDIES* 2018, VOL. 33, NO. 3, 643–662, p. 658.

[99] Johanna Hedva, ‘Sick Woman Theory’, *Mask Magazine*, 2016 <http://www.maskmagazine.com/not-again/struggle/sick-woman-theory> [accessed 16 September 2019].

The groups invoked by Hedva as being cut off from modes of protest deemed political from an Arendtian standpoint of taking 'public' action are the ill and disabled, but also the precarious workers, the incarcerated, those with a lot of caring responsibilities, and people at risk of hate crimes and police brutality. Hedva distinguishes between those who are 'imprisoned by a job' and those who face 'the threat of being fired from their job if they marched', indicating the multiple ways work can constrain personal autonomy.[100] It is common for workers to be banned from making public political statements and be penalized (officially or unofficially) for certain behaviours in their personal lives, indicating how the need for employment can control lives and behaviours even far outside working hours. Interestingly, being 'imprisoned' by a job due to extreme and inflexible working hours and being unable to publicly hold political opinions are commonly enforced for both low-paid and high-paid jobs, suggesting the conscription of personal choice and fear for job security even in jobs that are not precarious.

Hedva's narrator in some way inverts the metaphor of illness as work by including precarious workers under a header of 'sick people'. They use the case of the involuntary commitment of Kam Brock, a 32 year-old black woman, to emphasise the connection between race and perceived 'sickness'. Brock was committed by police officers in New York City in 2014 for being 'delusional' because she mentioned that she worked in a bank and Barack Obama followed her on Twitter (both of which were true). As Hedva's narrator writes, 'according to this society, a young black woman can't possibly be that important – and for her to insist that she is must mean she's "sick"'.[101] The narrator emphasises the elements of racial

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[100] Hedva, 'Sick Woman Theory'.
[101] Hedva, 'Sick Woman Theory'.

and gender bias by the police in the case, but employment status also plays a key role in the case; the police became suspicious of Brock due to her claim of working in a bank. Brock's chart from Harlem Hospital, obtained by her lawyers, makes it clear that Brock's claim of employment registers to the police as a lie and thus leads to her arrest. Their assumption of her unemployment in central to her committal, as it describes 'patient's weaknesses: inability to test reality, unemployment'.[102] Her treatment plan has the following objective: 'Patient will verbalize the importance of education for employment and will state that Obama is not following her on Twitter.' The category of 'sickness', as Hedva demonstrates, is used to police societal hierarchies and enforce ideas of the 'normal' by punishing those seen as 'deviant', and employment status is central to this.

Hedva describes 'Sick Woman Theory' as defending the inherent value of all bodies who have suffered under the 'current regime of neoliberal, white-supremacist, imperial-capitalist, cis-hetero-patriarchy'.[103] As Hedva writes:

> The Sick Woman is all of the "dysfunctional," "dangerous" and "in danger," "badly behaved," "crazy," "incurable," "traumatized," "disordered," "diseased," "chronic," "uninsurable," "wretched," "undesirable" and altogether "dysfunctional" bodies belonging to women, people of color, poor, ill, neuro-atypical, disabled, queer, trans, and genderfluid people, who have been historically pathologized, hospitalized, institutionalized, brutalized, rendered "unmanageable," and therefore made culturally illegitimate and politically invisible.[104]

By placing the idea of being 'rendered "unmanageable"' last, Hedva posits 'sickness' as a label applied to those seen to escape the disciplinary power of authorities and societal norms. Hedva finds illness to be emblematic of other 'sickness' because it mostly clearly shows the capitalist interests at play. As they

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[102] 'Kam Brock NYPD Incident', *Snopes.Com* <https://www.snopes.com/news/2015/09/14/kam-brock-nypd-incident/> [accessed 26 October 2022].
[103] Hedva, 'Sick Woman Theory'.
[104] Hedva, 'Sick Woman Theory'.

write: ‘The “well” person is the person well enough to go to work. The “sick” person is the one who can’t’. [105] Similarly to Boyer’s characterisation of illness as an entry point to a feeling of exhaustion of the ‘proletarianized all’, in Hedva’s essay the metaphor of the Sick Woman as a precarious worker allows the Sick Woman to become the archetype of the disenfranchised working class.

Illness is useful as a privileged category because it most directly suggests the resistance Hedva imagines: to stay in bed ‘until there is no one left to go to work’ and capitalism ‘will screech to its much-needed, long-overdue, and motherfucking glorious halt’.[106] A general strike, propelled by imagining a shared ‘sick’ identity. Hedva aligns a refusal of what Robert McRuer has called ‘compulsory able-bodiedness’ to a problematization of work as the marker of ideal capacity, and comes to a radical conclusion: if no one leaves their bed, this may be even more forceful than throwing bricks through the windows of banks. If no one comes to work, capitalism must crumble. Within this logic, sick bodies become, as an early description of the essay has it, ‘the 21st century’s sites of resistance [...] against the unlivable conditions of neoliberal, imperialist, white-supremacist, capitalist cis-hetero-patriarchy’.[107]

Hedva’s description of what it means to live with their own chronic illnesses heavily focuses on management work and the medicine they have to take ‘to be able to hold a job – which this world has decided I ought to be able to do’.[108] But the

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[105] Hedva, ‘Sick Woman Theory’.
[106] Hedva, ‘Sick Woman Theory’.
[107] *My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want It to Matter Politically*, dir. by Johanna Hedva (Los Angeles: Women’s Center for Creative Work, 2015) <https://vimeo.com/144782433>.
[108] Hedva, ‘Sick Woman Theory’.

conclusion of the essay marks a shift from individual self-management to collective 'infrastructures of care'. 'The most anti-capitalist protest', Hedva writes,

> is to care for another and to care for yourself. To take on the historically feminized and therefore invisible practice of nursing, nurturing, caring. To take seriously each other's vulnerability and fragility and precarity, and to support it, honor it, empower it. To protect each other, to enact and practice community. A radical kinship, an interdependent sociality, a politics of care. [109]

This collectivity is built by prioritising historically gendered and precarious care and reproductive work over jobs creating value for employers. Hedva's utopian description imagines a shift away from production with the aim of profit towards care work undertaken for the good of the community. It makes the reproductive work entailed by illness generalisable, shared between all. Hedva thus elevates the importance of the work of managing illness, but without positioning it as a training ground for more prestigious types of employment. Hedva builds on Judith Butler's work distinguishing between *precariousness* as a shared human condition of vulnerability and interdependence and *precarity*, manufactured inequality ensuring the concentration of wealth among a small group. The 'Sick Woman' becomes an expansive metaphor for all those who suffer precarity, while embracing precariousness becomes the way to unite around a different organisation of community.

The alliances forged between precarious workers and the chronically ill in both Hedva's and Boyer's texts foregrounds the negative affinities between the conditions of being ill and being employed—those of exploitation and precarity—and follow the metaphor to its implications of labour activism, unionising, and worker revolt. This anticipates recent manifestos on leftist health politics such as

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[109] Hedva, 'Sick Woman Theory'.

Beatrice Adler-Bolton and Artie Vierkant's *Health Communism* (2022). Adler-Bolton and Vierkant argue that breaking the binary of worker versus what Ruth Wilson Gilmore calls the 'surplus'—the populations marked out as unproductive and therefore as beneficiaries rather than contributors to the body politic—should be central to anti-capitalist politics. They write:

> We've been told that work will heal us. We've been tricked into trying the work cure. We are told that work is in our best interest, when the truth is that it only serves the needs of capital and the ruling class at the expense of our health. Breaking the mirage of worker versus surplus provides a revolutionary opportunity to unite surplus and worker classes in recognition of a better truth: safety, survival, and care are best ensured outside of capital. This revolutionary potential has been divided, discouraged, and criminalized.[110]

The metaphor of chronic illness as a type of precarious work forges this connection and thus affords political resistance, at least on a symbolic level.

Other contemporary feminist illness writers similarly use metaphors related to union activism. Huber describes illness as her body 'going on strike'.[111] 'If the work ethic seeks executive control from the top down, chronic illness throws wrenches in the machinery, stops the presses, throws up pickets and foments dissent', she writes.[112] UK artist Laura Cowley's project *The Union for the Useless*, created for people with chronic illnesses or disabilities who 'work to undermine the glorification of national productivity' similarly borrows the forms of labour activism to create a union replete with rules for membership, patches, and union banners.[113] The idea of a union for the ill is not new: feminist activists in the 1970s and '80s organised health collectives and health unions which contributed to promoting

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[110] Beatrice Adler-Bolton and Artie Vierkant, *Health Communism* (London: Verso Books, 2022), p. 240 (p. 57).

[111] Huber, p. 33.

[112] Huber, p. 47.

[113] Laura Daisy Cowley, *The Union for the Useless*, 2018 <https://www.lauradaisycowley.com/#/unionfortheuseless/>.

patient rights, reproductive care, and public health initiatives.[114] The ways in which contemporary writers are reviving these ideas now, invoking this feminist legacy, makes clear the ways in which fourth-wave feminism builds theoretically on second-wave feminist organizing.

Contemporary feminist illness writing is aligned with recent anti-capitalist health-focused manifestos, but also offer counterpoints to them in certain ways. In those texts as in much leftist writing, chronic conditions and disabilities are often used as metaphors for the consequences of capitalism in ways that have been criticised by disability and illness advocates. A manifesto like the French leftist autonomist The Invisible Committee's *The Coming Insurrection* (2007) for example, describes mental illness both as a condition created by capitalism and a means to resist it. 'We are not depressed,' the manifesto claims, 'we are on strike. For those who refuse to manage themselves, 'depression' is not a state but a passage, a bowing out, a sidestep toward a political disaffiliation'.[115] Merri Lisa Johnson calls this kind of claim made by The Invisible Committee, typically made by people who do not have personal experiences of mental illness, the 'madness-as-protest metaphor' and argues that it is harmful.[116] As other feminist scholars have agreed, this metaphor can flatten the reality of mental illnesses like depression and anxiety by explaining them as simply responses to circumstances rather than conditions which have a number of different aetiologies.[117] Moreover, it can portray illness as a political choice and trivialize the real suffering of people who live with these conditions by describing

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[114] Jennifer Nelson, *More Than Medicine: A History of the Feminist Women's Health Movement* (NYU Press, 2015) <https://www.jstor.org/stable/j.ctt15r3z67> [accessed 12 March 2023].

[115] The Invisible Committee, *The Coming Insurrection* (Los Angeles, CA: Semiotext(e), 2009). Emphasis in original.

[116] Merri Lisa Johnson, 'Bad Romance: A Crip Feminist Critique of Queer Failure', *Hypatia*, 30.1 (2015), 251–67 (p. 253).

[117] Elizabeth J. Donaldson, 'The Corpus of the Madwoman: Toward a Feminist Disability Studies Theory of Embodiment and Mental Illness', *NWSA Journal*, 14.3 (2002), 99–119; Andrea Nicki, 'The Abused Mind: Feminist Theory, Psychiatric Disability, and Trauma', *Hypatia*, 16.4 (2001), 80–104.

them in the abstract. As Tanja Aho argues, manifestos like *The Coming Insurrection* foreclose a crip futurity; it is implied that a society without capitalism will also be a society without mental illness.[118]

In the case of physical chronic illness, however, the metaphor is less problematic. Physical illness remains less stigmatised than mental illness, and the metaphor is less likely to be read as implying that illness is a political choice. The deficiency model of physical illness maintains that illness is a fault in an individual body, and writers like Hedva and Boyer are interested in putting more emphasis on the environmental and political factors that can contribute to it. I will return to the questions of ill and disabled (crip) futurities in Chapter 5, which posits utopian illness writing alongside post-work and environmental imaginaries. Overall, then, the metaphor of the sick woman as precarious worker affords collective action and organising, breaking the capitalist opposition between worker and surplus. Offering a counterpoint to metaphors of illness as 'management' job or a 'career', it provides an alternative explanation to why the metaphor of illness as work has become ubiquitous. This posits illness not only as active and skilled activity but also as disenfranchised and boring: offering only the illusion of personal agency, while in reality being a heavily governed domain.

Metaphors, forms, and non-teleology

The use of metaphor in these texts connects to an exploration of how the right level of generalisation can strike a balance between telling an individual's story and galvanizing collective struggle. In Boyer's *The Undying*, the narrator contrasts different ways of telling stories about illness. The traditional way is the teleological

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[118] Aho, p. 157.

narrative as described in Chapter 1. ‘To tell the story of one’s own breast cancer,’ she writes, ‘is supposed to be to tell a story of “surviving” via neoliberal self-management—the narrative is of the atomized individual done right’.[119] The narrator thus links Frank’s ‘quest narrative’ to a neoliberal idealisation of the individual and their agency, similarly to the critiques from theorists.[120] She writes that she does not want to write her own story, since ‘to write only of oneself’, she argues, is

> to write more specifically of a type of death or a deathlike state to which no politics, no collective action, no broader history may be admitted. Breast cancer’s industrial etiology, medicine’s misogynist and racist histories and practices, capitalism’s incredible machine of profit, and the unequal distribution by class of the suffering and death of breast cancer are omitted from breast cancer’s now-common literary form.[121]

The illness memoir as a story of individual overcoming of difficult circumstances obscures the structural inequalities of illness. Instead, Boyer’s narrator states that she wants to write about having ‘a body in history’, a story about her illness which incorporates both personal and structural aspects.[122] This formulation of ‘having a body in history’ is not fully unpacked in the text. It is one of a number of different formulations attempting to capture the balance between specificity and generalisation, and to create a literary form which can hold both. In the text, illness has different levels: the specific breast cancer at the centre of the story, pain as a broader gendered and racialised phenomenon, and the condition of being sick and tired as a phenomenon that can illuminate an increasingly common, class-based experience of the deep exhaustion stemming from being exploited under capitalism. The necessity of including the personal story reflects Haraway’s statement that ‘the

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[119] Boyer, *The Undying*, p. 9.
[120] See e.g. Woods, Wasson, Hyvarinen and others.
[121] Boyer, *The Undying*, p. 10.
[122] Boyer, *The Undying*, p. 261.

only way to find a larger vision is to be somewhere in particular' and the emphasis on embodiment and positionality as described in Chapter 1.[123] But while the standpoint is acknowledged, it must not dominate or centre the self. It needs to also include the realities of wider structural inequality, such as stories of racism, classism, misogynism, and the ways in which these are imbricated with capitalism and medicine. This, as Boyer's narrator acknowledges, provides a challenge to the traditional literary form of the illness memoir focused on individual development.

As an alternative to the story of the individual, the narrator describes wanting the text to be more unruly. Instead of being 'testimony', she wants the text to be an experiment in using many different literary forms as 'a record of the motions of a struggle to know, if not the truth, then the weft of all competing lies'.[124] This aligns with Levine's description of literary texts as 'inevitably plural': including a multitude of smaller forms that collide in often surprising ways. Boyer's concept of writing about death is close to Butler's definition of precariousness and Hedva's icon of the Sick Woman. It is what leads to the stated aim of writing about 'exhaustion':

> Exhaustion is a culmination of history presented in one body, then another, then another. If exhaustion as a subject has become newly popular it is because a once-proletarian feeling has now become a feeling of the proletarianized all.[125]

When the story of illness is told as a story of collective struggle, Boyer writes, 'illness becomes the undeniable challenge to revolutionize everything—yes, everything!—for the first time really and in the right way'.[126] There is a sense that the many different forms are required for this new type of illness text to contain the complexities of the contemporary experience of illness. As the different metaphors

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[123] Haraway, p. 590.
[124] Boyer, *The Undying*, p. 285.
[125] Boyer, *The Undying*, p. 246.
[126] Boyer, *The Undying*, p. 274.

analysed in the first sections of this chapter demonstrate, the ill person lives in an over-determined and very complex relationship to ideals of personal agency, work, and societal value, all of which are imbricated with the concept of work. The concept of the illness text as proletarian history breaks with both neoliberal emphasis on individual responsibility and the illness memoir as teleological narrative.

In this chapter, I have argued that the discourse of illness as work—as expressed through the different metaphors—speaks to a number of related cultural changes: the rise of neoliberalism and neoliberal constructions of subjecthood; an increase in 'patient work' due to technological advances and cost-cutting measures; and a change in the 'sick role' from one that emphasises submission to the medical establishment to one in which the ill person must project-manage their own illness. These are all developments which happen alongside the development of the illness memoir as a genre in the second half of the twentieth century. The two are imbricated, as can be seen in how the teleological narrative of personal development is a story of the ill individual finding a way to make returns on their illness. This narrative is thus closely related to ideas of the self as enterprise as described by Foucault. However, while neoliberal ideology is still thriving in the popular culture and politics of the 21st century, many commentators describe an increasingly widespread fatigue and a political disillusionment with it.[127] The financial crisis of 2008 has been termed the 'death of neoliberalism' as the illusions of the free market as self-regulatory was shattered by the necessity for banks to be bailed out by the state. An increasing number of people are looking for alternative societal models centred on sustainability and community. The rejection of the type of illness

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[127] Manuel B. Aalbers, 'Neoliberalism Is Dead … Long Live Neoliberalism!', *International Journal of Urban and Regional Research*, 37.3 (2013), 1083–90; Ganesh Sitaraman, 'The Collapse of Neoliberalism', *The New Republic*, 23 December 2019.

narrative most closely aligned with neoliberal values is linked to this disillusionment, with non-teleological, fragmented illness texts seeking alternatives to literary models that emphasise individuality and growth.

As I have argued, the discourse of illness as a career posits it as a field in which there is progression to be made subject to skill and dedication. By contrast, describing the ill person as a precarious worker presents illness as profit-driven, exploitative, and suffused with structural inequality. Foucault describes the formation of neoliberal ideology as dependent on a shift in point of view. Neoliberal economists, he argues, decided to look at the labour market from the perspective of the worker as an 'active economic subject' rather than as an object in it.[128] Economists chose to inhabit the individual worker and describe how the world, and the market, looked from their point of view, rather than from a top-down view of the market. This in turn led to the understanding of individual subjects as entrepreneurs, 'a society made up of enterprise-units'.[129] Post- and anti-work political theorists such as Kathi Weeks argue that this made it more difficult to think about work at scale; as she writes, thinking within neoliberal ideologies 'we often experience and imagine the employment relation—like the marriage relation—not as a social institution but as a unique relationship'.[130] But just as second-wave feminist thinkers had to generalise to demonstrate how even something as individual as a marriage is shaped by structural forces and entrenched gender roles, Weeks argues that one way out of neoliberalism is a reverse move, switching the point of view from the individual worker back to considering relations of employment on a structural level. Describing the ill person as a precarious worker presents them as determined by a whole system

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[128] Foucault, *The Birth of Biopolitics*, p. 223.
[129] Foucault, *The Birth of Biopolitics*, p. 225.
[130] Kathi Weeks, *The Problem with Work: Feminism, Marxism, Antiwork Politics, and Postwork Imaginaries* (Durham: Duke University Press Books, 2011), p. 3.

which they do not have the power to change on their own, but which a large group of people have common interests in changing together.

This reversal, underpinned by the metaphor, allow writers to describe work—and by extension illness—as a structurally constructed social institution which needs to be changed wholesale. This also underscores why contemporary illness writing specifically seizes on second-wave feminist theory. Changing the representation of contemporary work from an individual investment and return of human capital back to a structural relation of power in which most of us have very little choice is crucial to political resistance. Contemporary feminist illness writers thus participate in both feminist and anti-neoliberal methodologies in their figurations of the sick person as a precarious worker. Figuring the ill person as a worker is a way of making them into a politicised subject who is justified in making demands. Figuring them as a *precarious* worker is a way of reaching beyond patienthood and emphasising the need for wider anti-neoliberal resistance.

Alice James exclaimed in her diary: ‘How well one has to be, to be ill!’[131] Being ill is still a highly demanding state and a contentious social role, as the metaphors analysed in this chapter have shown. The active sick role has had large implications for those inside medical systems, creating more ‘patient work’ and more responsibilities in terms of co-ordinating one’s own care and project-managing one’s illness. However, for those on the margins of the medical system, the onus to be proactive can be even more complex. Those who are ill with contested conditions, conditions which are poorly understood or currently untreatable, and those who do not yet have a diagnosis are often forced to undertake large amounts of investigative labour. This is labour which presses even closer to simply being work; often

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[131] James, *The Diary of Alice James*, p. 129.

stemming from medical neglect, many contemporary illness texts describe patients being forced to step into the remit of the doctor and undertake labour which is typically done by professionals. In Chapter 3, I will examine this labour and the literary form in which they often appear: the list. Investigative labour is often described in contemporary feminist illness writing in the form of long lists—of symptoms, of treatments, of strategies which have failed. I look at these lists as examples of non-teleological narrative form, one of the forms that recur in contemporary feminist illness writing. The list, as I will show, is closely connected both to medical literary forms, distinctions between disease and illness, as well to the origins of life-writing in accountancy.

Chapter 3: Listing disorder: illness work on the margins of medicine

In Porochista Khakpour's *Sick,* much of the text is taken up by descriptions of the narrator going to see different doctors, trying out various medications, gathering information from other people with similar illnesses, and experimenting with alternative providers and treatments. Some of the efforts she has gone to in attempts to manage her un- or misdiagnosed symptoms or untreatable illnesses are recounted in a list-like paragraph, which describes a particularly desperate time in the narrator's unhealth:

> I became someone whose main job was trying out medications and going to the doctor. It was like shopping in a way: I found myself spending a full day googling and consulting friends on Seroquel, an antipsychotic I'd been prescribed—which back then was fairly new and had all sorts of black box warnings—only to refuse it in the end. I tried out antidepressants with names like sci-fi wizard goddesses, Paxil and Celexa, and always felt moments later that my entire body was burning, quickly discovering that I was someone who came down with severe neuropathy when it came to SSRIs. I tried every natural supplement you could find in a Whole Foods. I tried acupuncture, I tried an ayurvedic center, I tried multiple healers, I tried nutritionists. At one point I was seeing three different sleep specialists who all seemed fairly invested in hiding how stumped they felt. I spent every penny I had searching for the energy to keep seeking.[1]

At every point, the memoir demonstrates the active role Khakpour has needed to take in managing and investigating her symptoms. The narrator describes getting a diagnosis as 'something of a labor already', but the diagnosis only leads to more labour, trying to find treatments that work for an illness that no one understands.[2]

There are two primary instances of figurative language used to describe this labour in the passage. The first is the discourse of illness as a job described in

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[1] Khakpour, p. 77.

[2] Khakpour, p. 1.

Chapter 2. But it is not her illness per se which is compared to work. Rather, it is the administrative and investigate labour related to researching treatments and diagnoses which becomes a 'main job' and adds up to a 'full day'. These formulations emphasise that she has other jobs and responsibilities, too, and that this type of labour takes up the entirety of her capacity. The administrative and investigative labour which the narrator describes, using the register of work, overlaps with some of the tasks included in the concept of 'patient work' discussed in the previous chapter. But as Khakpour's recounting makes clear, much of her labour takes place outside a sanctioned sick role, a formal patient-doctor relationship, and the parameters of biomedical knowledge.

The paragraph starts at the centre of the system—'trying out medications and going to the doctor'—but as the list progresses, the narrator describes more alternative and experimental approaches. She finds herself needing to push back against medical advice, refusing and stopping prescriptions because they do not work for her, despite medical advice. The grammatical structure of the sentences underlines her own agency and responsibility: nine of the clauses have 'I' as the grammatical subject. We are not told whether a doctor is involved in the realisation that she reacts badly to SSRIs (selective serotonin reuptake inhibitors); this is framed as her own discovery. The only action in the paragraph ascribed to healthcare professionals is their investment in 'hiding how stumped they felt'. The disparity between the activity of the two parties is extreme, something that presents the narrator as alone in being dedicated to figuring out how to manage her condition.

Like many other people living with contested, undiagnosed, or untreatable conditions, Khakpour is not only forced to take a very active role in her illness (as described in Chapter 2), but also to develop her own knowledge through trial and error, and through ‘googling and consulting friends’. Chronic illnesses are conditions which the medical establishment cannot currently cure, which means that there is a gap in knowledge, sometimes filled by the patients themselves and their information-sharing. They must often break new ground, share knowledge about treatments, and stay up to date on new research.[3] This can create conflicted clinical encounters; when doctors and patients are on equally shaky grounds, traditional hierarchies of knowledge and divisions of responsibility come under pressure. This is indicated by Khakpour’s narrator, who describes taking over responsibilities traditionally carried by professionals, including monitoring the efficacy of her medications and making decisions about which prescriptions to accept seemingly on her own. The second instance of figurative language used in the passage for the labour she is doing, that it was ‘like shopping in a way’, compares the ill person to a consumer, with the doctors as merchants. This describes her own agency as supreme and solitary; the doctors and alternative providers offer various solutions, but the ill person shops around between them, with the responsibility to discern what is reasonable and potentially effective and what is a money-making scheme.

Being in this difficult subject position with the labour of undertaking research, checking doctors’ recommendations, and trying out treatments is particularly prevalent in the US, where the privatized health care system encourages consumer behaviour among patients. It is also exacerbated in mysterious or contested illnesses, where the ill person often cannot rely on the recommendations and knowledge of healthcare staff. However, it also illuminates how the patient role has changed with access to medical knowledge and the newest research on the

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[3] Chris Allen and others, ‘Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers’, *Journal of Medical Internet Research*, 18.3 (2016).

Internet, as well as the information-sharing and emotional support taking place in online communities. Moreover, it demonstrates how being ill often takes place both within and without sanctioned biomedical realms, and that the labour entailed by illness also extends past these boundaries.

The investigative labour described by Khakpour and others in this chapter is a form of reproductive labour in the sense of contributing to the daily effort of reproducing the self, but this term does not capture its specific relation to illness. There is no official term for this type of labour, which means that it is largely opaque to healthcare staff and the social scientists studying 'patient work' and 'the burden of treatment', which includes items such as 'learning about my condition or treatment' and 'plan and organize self-monitoring' but not undertaking experimental strategies or diagnostic research (even if it does include the stress of dealing with doctors who are perceived as neglectful or which do not understand the particular condition).[4] Much of the labour takes place before a diagnosis is given, meaning that those who are ill are not even registered as such in any official systems, making it difficult to measure. Illness writing is thus one useful source to understanding it. In this chapter, I use formulations such as investigative illness labour or reproductive illness labour to avoid the gate-keeping properties of the concept of 'patient,' and to distinguish it from the type of labour described in Chapter 2.

Many recent illness memoirs document the practical and affective consequences of having to undertake investigative illness labour. In this chapter, I look at how texts by Khakpour, Abby Norman, Sarah Ramey, Meghan O'Rourke, Amy Berkowitz, and Dodie Bellamy describe the difficulty of researching and experimenting with treatments and strategies. While this labour shows up in different

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[4] May and others; Tran and others.

ways throughout the texts, I focus on a particular form in which it recurs: the list, which also structures the passage quoted above. Drawing on Caroline Levine's analysis of forms as 'patternings, shapes, and arrangements' which afford the organisation of materials in particular ways, I look at why the list is so often favoured as a form to represent the investigative labour related to mysterious illness.[5] Although the lists take different forms—case histories, lists of symptoms, BuzzFeed-like listicles, more narrative lists— there is nonetheless something to be said for the list as a recognisable form with particular structuring properties. As Levine writes, 'a bridge, a weekly schedule, a segregated school, a network of railways—these are all ways of arranging bodies and goods. They are constructed; they are artificial; they organize materials'.[6] The list, like these other forms, has certain affordances; it has a series of items, arranged in a certain order. As Khakpour's list quoted at the beginning of this chapter shows, each item on a list can be a condensed story, perhaps months of efforts, hopes, and disappointment, reduced into a word or a phrase—stripped of some information, but put into a new context through the arrangement of the list. That is not to say that lists only create order, however; below, I explore both the list's ordering and disordering affordances as they manifest in contemporary feminist illness writing to explore the burden of investigative illness work.

Chapter 1 looked at the reflexive descriptions of the embodied work of writing as one example of the non-teleological narrative models which contemporary feminist illness writing uses as an alternative to stories of personal development. This chapter looks at the list as another non-teleological form favoured in

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[5] Levine, *Forms: Whole, Rhythm, Hierarchy, Network*, p. 13.
[6] Caroline Levine, 'Forms, Literary and Social', *Dibur Literary Journal*, 2, 2016, 75–79 (p. 75).

contemporary feminist illness writing, through which the texts explore the practical and affective dimensions of the labour of searching for a diagnosis and managing symptoms. The form of the list, I argue, is used by contemporary feminist illness writers to undercut the teleological narrative, eschewing stories of causality for the representation of the intensification of affects and the building of strain over time. Levine describes literary texts as ‘sites, like social situations, where multiple forms cross and collide, inviting us to think in new ways about power’.[7] Each section of this chapter finds the use of lists in collisions between the experience of undertaking investigative illness labour and other textual and social forms.

In the first section, I look at the collision between the active sick role and medical lists and the medical knowledge they structure. I argue that texts by Abby Norman, Sarah Ramey, and Amy Berkowitz use lists to document contemporary socialisations of the sick role in contested chronic illness, but also to navigate the conflicts that can arise from existing at the limits of medical knowledge or being victim to medical neglect. The second section explores the collision between the experience of chronic, mysterious illness and teleological illness memoir. Here, I return to and elaborate my analysis of the refusals of endings seen in contemporary feminist illness writing as begun in previous chapters, arguing that an ending of ‘overcoming’ illness is often negated or replaced by a list. The third section looks at how pressures to be a ‘good’ patient intersect with the affordances of life-writing, specifically its connections and affordances to moral ‘accountancy’, confession, and persuasion. In contemporary feminist illness writing, this results in lists of evidence that the ill person takes responsibility for their illness, but also counter-lists of the ways in which they have broken the ‘rules’ of ‘good’ patienthood. The last section

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[7] Levine, *Forms: Whole, Rhythm, Hierarchy, Network*, p. 122.

looks at how lists are used to represent a particular experience of labour—something Levine describes as its own form, a type of social rhythm—which is precarious and builds strain over time.

Going away from the more abstract ways in which contemporary feminist illness writers position illness as work or labour—claims, arguments, metaphors—in this chapter I thus turn to the labour of illness in the concrete. The subjects of the lists are the daily tasks which make up the 'evidence' for the larger claims of illness as precarious reproductive work. The lists therefore often represent the more repetitive, boring, lengthy, and descriptive parts of the text. They embody the fact of chronic illness writing often consisting only of the 'middle' in a traditional storytelling arc, as Khakpour writes.[8] However, I argue that the prevalence of these passages, and the way they illuminate the great variety of different efforts which make up the labour entailed by chronic illness, rather than just those undertaken within the medical system, mean that they deserve critical analysis.

Medical lists, medical knowledge

Lists are important in medicine. Due to the often highly technical and complicated nature of medical information, lists have become a favoured way to present data in a clear, simple, and concise manner. Lists appear in many places in routine medical work: checklists, guidelines, case histories, lists of medical effects and side effects, to name a few types of medical lists. Lists may help to avoid confusion, ensure consistency and accuracy, and improve patient safety, as Atul Gawande argues in *The Checklist Manifesto* (2009). But other thinkers have argued that over-reliance on lists simplifies ill people's stories and fails to capture the nuance and complexity of

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[8] Khakpour, p. 251.

their experiences. Rita Charon's concept of narrative medicine is developed at least partly as a response to the 'listification' of medicine; in *Narrative Medicine* (2008), Charon contrasts what she calls 'narrative' with more rigid forms like the list and the formula. She writes:

> Narrative, by its nature, is disruptive. Unlike lists or formulas, narrative is not clean, predictable, or obeisant. […] Not only through its ordering impulses but also through its disordering ones, narrative can help one see newly and for the first time something concealed, something overlaid, something buried in code.[9]

By categorizing information into often pre-defined lists, patient narratives are condensed in ways that cannot fully capture the extent of their symptoms, emotions, and circumstances. The use of lists can downplay the individuality and unique aspects of each patient's case, potentially leading to inaccurate diagnosis or treatment. Charon argues that 'narrative'—here meaning prose, conversation, storytelling—reveals tensions that lists gloss over. She therefore argues that healthcare workers need to be attentive to the emotions and internal conflicts buried in patients' stories about themselves and their illnesses.

However, literary lists can create disorder as much as order, as Foucault demonstrates through analysis of Jorge Luis Borges' short story 'The Analytical Language of John Wilkins' (1942) in the 'Preface' to *The Order of Things* (1966). Foucault describes the effect of a taxonomy of animals as described by 'a certain Chinese encyclopedia' whose illogical categories make impossible any type of actual ordering of items into boxes. As he writes, this 'absurdity destroys the *and* of enumeration by making impossible the *in* where the things enumerated would be divided up'.[10] While lists are often associated with serving as a more ordered, comprehensive complement to our memories—the to-do list, the grocery list, a list of

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[9] Charon, *Narrative Medicine*, p. 219.

[10] Michel Foucault, *The Order of Things* (New York: Vintage Books, 1994), p. xvii.

participants—this association also allows for the creation of disorder when the list does the opposite of what we expect it to do. The literary list can be used very differently to the medical list, but its affordances as a form are in holding information and structuring it in more or less apparent ways. Robert Belknap defines a list based on these principles:

> At its most simple, a list is a framework that holds separate and disparate items together. More specifically, it is a formally organized block of information that is composed of a set of members. It is a plastic, flexible structure in which an array of constituent units coheres with specific relations generated by specific forces of attraction. Generally such structures may be built to appear random, or they may be organized by some overt principle.[11]

As Belknap observes, while the list always orders its items in some way by putting them together, it also prompts the question of the specific relation between and cohesion of those items. It implicitly asks what, if any, 'forces of attraction' have generated a particular list. The list thus has functions and affordances; its limitations are also what makes it useful in certain contexts.

Whereas medical lists often make their organising principles overt, literary lists such as those commonly found in contemporary feminist illness texts often exploit the whole range of affordances of the list form in creating both order and disorder. The disordering form of the literary list will be elaborated in more detail in the next section. This section instead focuses on the ways in which contemporary illness writers respond to medical lists, sometimes by using their own literary lists. That lists are often used in significant ways in contemporary illness writing has been observed by other critics. Anne Rüggemeier argues, in an article on the use of lists in comics about terminal illness, that 'one reason for [the list's] surfacing in illness narratives might be the fact that lists play an important role in medical contexts,'

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[11] Robert Belknap, 'The Literary List: A Survey of Its Uses and Deployments', *Literary Imagination*, 2.1 (2000), 35–54 (p. 35).

where they help ‘translat[e] the disease, the care of the ill person and arguably the sick persons themselves into a discourse in which they are controllable and “manageable”’.[12] This observation suggests the ways in which these lists function to negotiate ideas of the ‘manageable’ body and patient. Chapter 2 explored how this discourse is embedded within ideas of top-down power, executive control, and the work ethic. But the ill person does not only have to manage themselves: they are also managed by the medical system, as described in the Introduction and Chapter 2.

There is much at stake in conforming or not conforming to medical lists. In Sarah Ramey’s *The Lady’s Handbook for Her Mysterious Illness* (2020), the medical list of symptoms is presented as a gate-keeping form which acts as an obstacle for someone with a contested illness. Ramey’s text describes a typical clinical encounter for what the narrator terms a ‘WOMI’ (a WOman with a Mysterious Illness). This figure, also called ‘Jane Doe’ in the text, is generalised from the commonalities between Ramey’s own experience of chronic illness and those of others she has met while ill. Ramey’s narrator thus employs the same kind of generalisation that theorists such as Charon criticise medicine for. As the WOMI lists her symptoms to a new doctor, a ‘scene unfolding in an office in your town every day, perhaps right now at this very moment’, she makes a ‘mistake’:

> The interaction begins very seriously, a furious scribbling of notes, a furrowing of the brow, a lot of nodding. The usual diseases are ruled out and Jane confirms she has been tested, twice, for everything under the sun. Her primary symptoms are severe constipation, distention and pain in the lower quadrant of her abdomen. As the doctor pages through her thick medical file, Jane takes the opportunity to share some of the stranger nonbowel symptoms she has experienced—aching in the bones, fatigue, itching, unexplained gynecologic symptoms, memory problems, lower back pain—but the words are scarcely out of her mouth before she wishes she had kept her addenda to herself. She can see the red flags rising behind his eyes, and the note taking slowly tapers off. Before she knows it, where once Sherlock Holmes

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[12] Anne Rüggemeier, ‘The List as a Means of Assessment and Standardization and Its Critical Remediation in Graphic Narratives About Illness and Care’, *CLOSURE: Kieler e-Journal Für Comicforschung*, 5, 2018 <http://www.closure.uni-kiel.de/closure5/rueggemeier> [accessed 5 July 2020].

> scribbled furiously, hot on the trail, bent on solving her mystery—he now leans back in his swivel chair, tip of his pen in the corner of his mouth, checking his watch. His look is saturated with understanding, for he has solved the case.
> What we have here is not a rare, tropical disease, Watson. What we have here is an unhappy woman, badly in need of an antidepressant.[13]

The WOMI's list is too long and too incongruous; the patient's list of symptoms deviates from the logic the doctor has been taught. Items like 'memory problems' and 'distention' do not connect according to what he has learned, and this undermines the trustworthiness of the whole list. The list is no longer reliable, and the doctor loses interest, leading to the conclusion that her physical symptoms must stem from mental health issues.

The scene describes a breakdown in communication in the clinical encounter. Two different lists, representing two different ways of thinking, collide and fail to translate into each other's register. The doctor is listening for a medical list of symptoms, a sanctioned form which although liable to change—symptom and diagnostic lists often develop significantly over time, with new diagnoses introduced and old ones removed—only has one true form at any given time. The fact that the patient fails to fit into this shows that the doctor described in the scene in fact expects a certain knowledge on part of the patient; he expects her to have made an accurate prioritisation of symptoms so that she can bring the most important, and the ones which fit together, to him. The patient instead delivers a different kind of list, not modelled on medical clustering, but instead including the symptoms which most seriously affect her. And perhaps her symptoms do not fit into any sanctioned diagnostic list at all.

In Ramey's description, the clinical encounter cannot contain uncertainty or be a site for the development of new knowledge co-created by the ill person and the

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[13] Sarah Ramey, *The Lady's Handbook For Her Mysterious Illness* (London: Fleet, 2020), p. 13.

doctor. The doctor in the scene simply concludes that it must be a psychological issue, and the patient is left with having to do the investigative labour of figuring out whether this is true or not. Ramey's generalised description of the clinical encounter is of course a worst-case scenario which documents medical neglect; a responsible physician would sort through the symptoms presented by the patient and do their best to figure out which clusters indicate underlying causes. It also exhibits a certain rejection of psychological illness as sufficient cause; the narrator looks specifically for a diagnosis of physical illness, likely because this is seen as more socially legitimate, as described in the discussion of illness hierarchies in Chapter 2. In this scene, the medical list is represented as a rigid form whose authority can be undermined by even slight logical deviations, but which is respected more highly by some doctors than the experiences expressed by their patients. This echoes Charon's description of the medical list in the passage above as a form that is shorthand for the unempathetic and reductive medical professional.

The importance of the (correct or incorrect) list in Ramey's scene is related to the heightened importance of lists when it comes to contested illnesses. In her memoir *Tender Points* (2015), Amy Berkowitz observes the significance of lists in the example of fibromyalgia, one of the diagnoses she has been given. Berkowitz cites the full diagnostic list for fibromyalgia in her text, including the fact that 'in order to be diagnosed, the patient must experience discomfort in at least 11 out of 18 tender points designated by the American College of Rheumatology'.[14] This reflects a typical structure of a diagnostic list which clearly sets out its criteria; one item more or less can mean the difference between diagnosis or non-diagnosis, and thus access to sick leave, accommodation, insurance support, and treatment. Whereas a

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[14] Amy Berkowitz, *Tender Points* (Oakland: Timeless, Infinite Light, 2015), p. 16.

disease is a condition in which the aetiology is known, the terms *disorder* and *syndrome* describe symptom clusters with an unknown biological basis.[15] Often, a disorder like fibromyalgia is understood medically simply as a matter of fulfilling the requirements of the given diagnostic list. Since the underlying causes are unknown, the list is of paramount importance to both the doctor and the ill person.

Having to follow the rules of a particular list can create difficulties if the ill person cannot translate their symptoms into items that correspond easily to the list. Berkowitz describes this as causing over-simplification of the complex reality of illness, which in her experience also has a psychological dimension rooted in trauma, specifically a rape at the hands of a paediatrician when she was ten years old. But the ill person is not rewarded for exploring the nuance and complexity of their experience, especially into the psychosomatic, she notes, but only for being easily legible in medical terms. As she writes, 'it's necessary to acknowledge that fibromyalgia patients are going to have an easier time being taken seriously by the system if they code switch and talk about their illness in precise, clinical terms'.[16] This means that those patients who can quickly adopt this language and the skill of navigating the clinical encounter will do better in the long term. The more contested the illness, the more 'professionalism' the ill person therefore needs to show to be taken seriously. Berkowitz's narrator learns to not bring up her psychological trauma; having both physical and psychological symptoms disturbs the logic of the list she is diagnosed in relation to, putting her in danger of losing access to accommodations for her physical symptoms.

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[15] Destiny Peterson and Jared W. Keeley, 'Syndrome, Disorder, and Disease', in *The Encyclopedia of Clinical Psychology* (John Wiley & Sons, Ltd, 2015), pp. 1–4 <https://doi.org/10.1002/9781118625392.wbecp154>.
[16] Berkowitz, p. 97.

The medical list as a site of negotiations is also explored in Abby Norman's memoir, *Ask Me About My Uterus: A Quest to Make Doctors Believe Women's Pain* (2018). Similarly to the list of investigative labour as provided by Khakpour in *Sick*, Norman's narrator uses a paragraph to describe the failed strategies undertaken to manage her illness:

> I tried birth control. I got an IUD. I did pelvic-floor physical therapy until it became too excruciating to continue. I have, in the name of pain management, had a varied assortment of objects inserted into my vagina: hands, garlic cloves, polished stone, colorful plastic 'expanders' that are actually just medical-grade dildos, slick transducers and icy speculums, catheters, swabs, scalpels, and gauze. I saw homeopaths and naturopaths and took all kinds of tinctures and pill-pods. I drank raspberry tea until I could no longer stand the smell of it. I tried castor oil packs, I tried TENs units (that is, transcutaneous electrical nerve stimulation), and I held electric heating pads against my bare skin until they burned me. I lived in, and for, hot bathwater.[17]

The long list describes Norman's experience of illness as an active, almost frantic state. The text recounts Norman's work to understand her symptoms, the research she undertook to be able to self-diagnose her condition as endometriosis, and her years of effort to find doctors who would take her seriously and provide her with the treatment she needed.

Her dependency on her own investigative work is echoed in the list; similarly to Khakpour's list, the mention of homeopaths and naturopaths suggest that a number of different actors are involved in prescribing these various remedies, but the subject of the clauses in the list is the first-person narrator. The repetition of actions and verbs emphasise her willingness to follow instructions, with various degrees of personal autonomy—'I tried' (three times), 'I got,' 'I did', 'I have [...] had [...] inserted' 'I saw', 'I took,' 'I drank', 'I held' and finally, if to underscore how these remedies have pervaded and structured every aspect of her life: 'I lived'. In using

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[17] Norman, p. 179.

this list to describe her compliance as a patient—even into the realm of the extremely painful—the narrator performs compliance while simultaneously questioning the efficacy of obeying medical orders.

By juxtaposing standard medical procedures such as an IUD with more extreme alternative treatments (garlic, raspberry tea) and those that are vague or undefined (‘all kinds of tinctures and pill-pods’) in the mini-lists that make up the overall lists, the narrator suggests an equivalence between these treatments on the basis of their inefficacy. As Norman’s text describes, the labour includes the daily reproductive labour of managing pain such as through hot baths, but it also includes project managing her condition (going to doctors, seeking second opinions, liaising with the state as she does not have insurance) and a more investigative role researching her condition in medical journals and on the internet. As described above, some of this labour can be seen as part of *patient work* or *the burden of treatment*. But the investigative effort, and to some degree the project management task, is work that should have been undertaken by medical staff. The narrator undertakes this work out of necessity and because of the medical neglect she is a victim of.

As in the texts by Khakpour, Ramey, and Berkowitz, *Ask Me About My Uterus* describes how the narrator is dismissed by older male doctors who do not see her as a reliable source and therefore do not believe that she is in as much pain as she says she is. This demonstrates a paradox in the contemporary socialisation of the ‘proactive’ patient role and the conflicts it is being asked to contain. She is tasked with taking control over her own illness, but when she shows up to the doctors with theories, experiments, and the newest research, this often, paradoxically, confirms her doctors’ suspicions that she is not legitimately ill. The narrator repeatedly clashes with doctors who are trained according to something closer to Parson's submissive patient role and thus are not comfortable to being challenged on their knowledge. As she writes, 'a frantic patient who has brought in a heap of research is often chastised, and usually advised to refrain from consulting Google'.[18] If patients are now often expected to develop a certain amount of lay expertise as part of the model called 'participatory patienthood,' these expectations are developed on a higher structural level and sometimes do not respond to the practices of doctors and other healthcare professionals.

Norman's narrator feels that her gender, lack of education past high school, working class background, and mental health history continually impact her treatment. Much of the medical neglect she experiences is due to doctors concluding that she must suffer from psychological trauma, owing to her low-resource family background with an abusive mother and a largely absent father. Convinced of this, the doctors dismiss her physical symptoms as psychosomatic manifestations of mental health issues. The text thus provides an example of how structural inequality and bias determines whose pain and symptoms are believed. This is supported in the social scientific literature which demonstrates that the quality of care given to patients is affected by bias relating to a long list of characteristics: race/ethnicity, gender, socio-economic status, age, mental illness, weight, having AIDS, whether the patient is perceived to have contributed to their injury or not, whether they are intravenous drug users, and whether they have a disability.[19] This shows that although patients are told they should be 'proactive,' that same behaviour that can be read as being a 'good' patient in some may be read aggression, overreaction,

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[18] Norman, p. 52.

[19] Chloë FitzGerald and Samia Hurst, 'Implicit Bias in Healthcare Professionals: A Systematic Review', *BMC Medical Ethics*, 18 (2017) <https://doi.org/10.1186/s12910-017-0179-8>.

malingering, exhibiting drug-seeking behaviour, hypochondria, or a sign of mental health problems in other patients or by other clinicians.[20]

In *Ask Me About My Uterus*, Norman uses the form of the list to develop and assert her own knowledge about her illness. It is through her own research and persistence that the narrator gets a diagnosis and access to treatment for endometriosis. As part of that process, she appropriates one of the most important genres of medical lists: the medical history. The narrator takes a job in a hospital archive and teaches herself to write down her own illness in the form of a case history:

> HX OF PRESENT ILLNESS: Patient is a 22-year-old gravida 0 para 0 female who complains of persistent RLQ pain that began in the fall of 2010. Pt reports cyclic pelvic pain, heavy menstrual periods, chronic nausea, progressively worsening fatigue and muscle weakness. She has also had frequent bouts of swollen cervical and supraclavicular lymph nodes, which may not be clinically relevant. She reports RIGHT-sided abdominal pain, which she indicates is at McBurney's Point, that is worsened by activity and sexual intercourse and not relieved with rest. Previous imaging studies did not reveal any indication of appendicitis.
>
> PAST MEDICAL HISTORY:
> - RIGHT-sided lipoma in lower back, not believed to be clinically significant
> - DX LAP 2010—endometriosis of the posterior cul-de-sac and LEFT paratubal ovarian cyst, aspirated and wrapped with Interceed. Torsion of LEFT fallopian tube
> - Significant unintended weight loss > 30 lbs
> - Hx of depression, anxiety, currently on Zoloft and in psychotherapy
> - Chronic nausea, early satiety
> - Chronic pelvic pain
> - Pelvic peritoneal endometriosis
> - Dyspareunia[21]

A case history is both a narrative form and a type of list. Except for length—a full case history would also include sections such as a family history, which Norman may have deemed unnecessary—this case history follows official guidelines such as given in the *Oxford American Handbook of Clinical Medicine* to begin with the chief

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[20] See also Nirmala Erevelles, 'Crippin' Jim Crow: Disability, Dis-Location, and the School-to-Prison Pipeline', in *Disability Incarcerated*, ed. by Liat Ben-Moshe, Chris Chapman, and Alison C. Carey (New York: Palgrave Macmillan, 2014), pp. 81–100.
[21] Norman, p. 181.

complaint, record the information in a particular sequence, and include specific details.[22] The writing of her case history is the moment in *Ask Me About My Uterus* when Abby properly takes control of her own treatment. Her use of this form, as well as of the medical terminology like ‘hx’ for history and ‘DX LAP’ for ‘diagnostic laparoscopy’ signifies not only her knowledge of her illness but that she is intruding on the work of a doctor, taking over the tasks they normally have responsibility for.

Arthur Frank describes how in modernist illness narratives, the use of medical terminology is part of a ‘narrative surrender,’ which is when the ill person submits to a medical narrative, accepting that being seen as ‘legitimately sick’ also entails ‘to tell her story in medical terms’.[23] Frank observes that in classic illness narratives, ‘the physician becomes the spokesperson for the disease, and the ill person's stories come to depend heavily on repetition of what the physician has said’.[24] But in postmodern illness stories, he argues, patients ‘can mimic [medical] language in a send-up of medicine that is shared with the physician’.[25] By writing down her symptoms with all of the authority of their Latin names, the narrator makes a claim for their importance in a language that carries the legitimacy and authority of medical knowledge. She finds and claims a diagnosis—endometriosis— although she stays within the medical form to do so. In taking the professionalisation of her role as a patient to the level where it is almost indistinguishable from that of a physician, she defends patients’ knowledge of their own bodies and the lived experience of illness.

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[22] John A. Flynn and J. M. Longmore, *Oxford American Handbook of Clinical Medicine* (Oxford; New York: Oxford University Press, 2007).
[23] Frank, p. 6.
[24] Frank, p. 6.
[25] Frank, p. 7.

The authority associated with some types of list and particular uses of language also plays an important role in *Tender Points*. Berkowitz considers structure in relation to texts about complex, contested illness. The narrator describes how she feels that more people would read her story if she used an appealing literary form like the listicle:

> When you have all this stuff you want to say, how do you get people to listen?
>
> There are thousands of blog posts about how to write compelling blog posts. Many of these posts discuss the practical benefits of writing listicles, or articles in the forms of lists.
>
> 9 Reasons to Use a Content Management System […]
>
> Listicles are a powerful way to drive traffic to your blog. People love listicles: They're fun to read and they're highly shareable via social media. The content is easy to digest and the authoritative headlines command respect.[26]

While listicles are still a common form of text on the internet, the mid 2010s when the text was written saw the rise of BuzzFeed and similar listicle-based websites which popularised the form. Frances McDonald proposes a distinction between the 'vertical,' ordinary lists such as to-do lists and grocery lists, which function as 'a protective ritual designed to overcome, or at the very least repel, the world's infinitude' and the 'horizontal' lists found in descriptions and other prose, which extend 'toward disarray and infinitude'.[27] In formally embodying the distillation of information across the internet into one accessible place, the listicle is a version of the 'vertical' lists of McDonald's description. Berkowitz's passage reflects the same desire to order and simplify information. It mimics the language and form recommended by the blog posts referenced in it, with short, clear sentences and

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[26] Berkowitz, p. 21.

[27] Frances McDonald, 'How to Read Lists (Well): A Response to Jed Esty', *Post45*, How We Write (Well), 2019 <http://post45.org/2019/02/how-to-read-lists-well-a-response-to-jed-esty/> [accessed 15 July 2020].

many line breaks. It also seems intentional that the first example in the passage is drawn from the corporate world of business, when Berkowitz is interested in the kinds of language that is simultaneously appealing and which is able to 'command respect'. Like describing the efforts and activities entailed by illness as a 'full-time job' or other term already occupying a role of prestige in society, using forms with associations to highly paid and valued work is a way of countering the negative judgments associated with chronic illness and contested disorders.

The narrator writes into a perceived reaction of mistrust and suspicion. The following pages after the passage on listicles are an attempt at such a list, called '4 Events You Miss Because of Fibromyalgia Pain'. But even in the listicle, which is supposed to be a lighter and more digestible form, the pain of not being believed finds a place. The section '2. Company Outing to the Roller Rink' includes the observation that 'Nobody believes you when you say you would love to go. Least of all your boss, who already worries that you're not a team player. But you really would love to go'.[28] The narrator then abandons the listicle form (although she takes it up again later), and tries various other forms, but none seem to strike the right balance between containing nuance but also speaking plainly in order to be understood. 'Poetry fails me because it's not written plainly', she writes, arguing that it is too closely associated with femininity to carry something as already suspect as a story about contested illness.[29] 'That's why I so firmly want prose here. Sentences. Periods. Male certainty. These are facts. No female vocal fry'.[30] As a form, the appeal of the list or listicle, in the narrator's description, seems to be its associations

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[28] Berkowitz, p. 22.
[29] Berkowitz, p. 24.
[30] Berkowitz, p. 25.

to clarity, order, and ease of consumption. These qualities are felt as necessary to communicate an experience of illness that is so often dismissed.

The form of the list thus holds a particular significance within illness writing, because it connects to the important medical lists which regulate the admission to diagnoses and determine what help and treatments those who are ill have access to. It comes to symbolise the desires of medical knowledge—to control, simplify, and generalise illness—but also the illusionary nature of this for the people who do not fit into a sanctioned list. Moreover, it becomes a form to be appropriated by those who are ill, whose use of this medical form signals their acquisition of medical knowledge and their taking over certain responsibilities from doctors who neglect these. This points to how the role of the patient has changed, not least due to the medical information available online, something that has also been shown by researchers.[31] All the texts analysed above reference the Internet or Google, showing how online information-sharing, but also forms which have emerged on the Internet, such as the listicle, have influenced the illness texts. Lastly, the use of lists is associated with discussions of how those who are chronically ill use language and literary forms to navigate a complicated social position. For someone who is living with the complex and unpredictable reality of contentious chronic illness, the associations and affordances of certain forms of list to make someone more easily

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[31] See C. Stults and P. Conrad, 'The Internet and the Experience of Illness', in *Handbook of Medical Sociology*, ed. by Chloe E. Bird, P. Conrad, and A. M. Fremont, 6th ed (Nashville, TN: Vanderbilt University Press, 2010); V. A. Crooks, '"I Go On The Internet; I Always, You Know, Check To See What's New": Chronically Ill Women's Use of Online Health Information to Shape and Inform Doctor-Patient Interactions in the Space of Care Provision', *ACME: An International Journal for Critical Geographies*, 5, 2006, 50–69; Flis Henwood and others, '"Ignorance Is Bliss Sometimes": Constraints on the Emergence of the "informed Patient" in the Changing Landscapes of Health Information', *Sociology of Health & Illness*, 25.6 (2003), 589–607 <https://doi.org/10.1111/1467-9566.00360>; R. J. Cline and K. M. Haynes, 'Consumer Health Information Seeking on the Internet: The State of the Art', *Health Education Research*, 16.6 (2001), 671–92 <https://doi.org/10.1093/her/16.6.671>.

legible—objective rather than subjective and emotional—are used to explore the pressures and possibilities of this subject position.

Writing disorder

The emphasis on describing investigative illness work is not unique to contemporary anti-teleological writers. Being told by doctors that there is nothing to do, but forging out on your own, expending significant labour to try different treatments, and doing your own research, only to succeed against all odds, is a familiar plot. It is a version of the archetypal teleological narrative of the hero's journey. Frank describes this plot as a version of the 'quest narrative' in *The Wounded Storyteller*, using the example of Norman Cousins's *Anatomy of an Illness* (1979). In this book, the narrator describes suffering from an acute inflammatory illness, rejecting doctors' conclusions that the condition is progressive and incurable, and, together with a physician friend, managing to successfully treat himself and overcome the illness. Frank describes this narrative as a form of automythology in which Cousins's curing of himself 'becomes metonymic for concepts of *perfectibility*, *regeneration*, and ultimately *the finest exercise of human freedom*'.[32] As Frank's choice of words suggests, this is also a medical version of the American dream, through which hard work and dedication leads to happiness and health.

As mentioned in previous chapters, contemporary feminist illness writers mostly reject this narrative. Texts usually emphasise circularity rather than progression, with some writers arguing that teleological narratives prioritise individual effort and victory over the more important structural changes that could have an effect in changing the system for everyone. This is also the case in

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[32] Frank, p. 125. Emphasis in original.

Norman's text. The text follows the hero's journey plot to the extent that the narrator does her own research, learns the skills she needs, figures out her own diagnosis, and finds a doctor who is willing to verify the diagnosis and get her treatment and support. Until this point, the text could be read as a classical automythology, in which the patient's hard labour pays off and helps her overcome adversity. But Norman chooses not to end the text here. Instead, the body of the text ends with the narrator becoming ill again with new symptoms and seeing another new doctor. As he dismisses her symptoms, she tells him how she has been dismissed before, repeatedly, but ended up diagnosing herself with a common illness. The doctor replies, ironically: 'Do me a favor […] When you figure out what it is, *let me know*,' again placing all responsibility on her.[33] The text thus ends with a repetition that points back to the beginning of the story, suggesting an endless cycle of illnesses and flare-ups—and endless investigative illness labour.

Although Norman specifically formulates her book as a quest, 'to Make Doctors Believe in Women's Pain,' this last clinical encounter recounted in the book underlines that the objective is far from achieved; the point of the text is to contribute to this aim post-publication. The text therefore omits a key component of the quest narrative, as the narrator's objectives are not achieved within the text. A difficulty with endings is described metatexually: an epilogue describes a scene of the narrator in the bath, 'trying to figure out how to end this story'.[34] To do so, she mentally goes over the lists she has made for herself at different points in her life. 'I know', she writes, 'because I am now and was then a devout list-maker—that I had a clear picture of what I hoped I could achieve if I put the legwork in to fix what

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[33] Norman, p. 270.
[34] Norman, p. 273.

needed to be fixed and give myself a solid enough foundation upon which to build the rest of my life'.[35] The list of goals and the list of action points to get to a particular goal are thus described as forms which provide a sense of control. These types of list afford breaking down complex matters into smaller items, and thus creates a sense of sequence and progression.

However, the complexities of health and illness escapes being controlled by the actions of list-making. The narrator realises the limitations of this approach, and the text ends without resolution, with only the reflection that she is still alive, for the time being. This marks a return to the present tense similar to the reflexive descriptions of embodied positionality described in Chapter 1. The text describes the way in which the story does not conform to her own expectation of illness stories, modelled on social narrative models such as Frank's quest narrative. But by reformulating the aim of the quest—from individual progression to systemic change—Norman nonetheless retains the understanding of the illness memoir as an active text which can effect changes, not within herself, but more generally.

The affordances and limitations of the list as a form are thus explored in *Ask Me About My Uterus*. The types of list which are supposed to be an aid to progression—to do-lists and lists of goals—fail when faced with the unpredictable rhythm of remission and relapse of chronic illness. Appropriation of medical lists is necessary, but only because of medical neglect, and becomes the clearest evidence of how the narrator's investigative illness labour is professionalised to the extent that it is virtually undistinguishable from the work of doctors. And as the teleological narrative fails, and no satisfactory ending is given which retrospectively organises the ill person's labour into necessary actions leading to a resolution, what is left is

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[35] Norman, p. 274.

the ‘middle’; labour, most of which has led nowhere. The list of failed investigative strategies and treatments cited earlier thus becomes a microcosm of the text as a whole as well as one of the textual forms that replace the teleological narrative. Moreover, it can be seen as a formal representation of how the chronically ill person is cast as a precarious worker, toiling without the possibility of progression, as described in Chapter 2.

The use of the literary list to represent the experience of foreclosed advancement and experiential confusion and exhaustion is even clearer in other texts. In the poem ‘Idiopathic Illness’ from Meghan O’Rourke’s poetry collection *Sun in Days* (2017), for example, a long list of different treatments and strategies for managing a long-term infection draws attention to the investigative work entailed by illness. The poem is almost all list, and similarly to Norman’s and Khakpour’s lists, it describes the strategies the speaker has tried in order to manage her undiagnosed illness:

> [I] went for IV drips, mercury detoxes, cilantro smoothies.
> I pressed my lips to you, fed you kale, spooned down coconut oil.
> I fasted for blood sugar, underboomed the carbs,
> chased ketosis, urine-stripped and slip-checked.
> Baked raw cocoa & mint & masticated pig thyroids.
> [...] I read about you on the Internet & my doctor agreed.
> *Just take more* he urged & *more*.[36]

The speaker lists a variety of treatments and strategies, ranging from established medical interventions (IV drops, urine-testing, research), common health remedies (kale, ketogenic diet) to more alternative treatments (masticated pig thyroids, mercury detoxes) and indeterminate actions or metaphors (‘I pressed my lips to you,’ with echoes of prayer or a rosary, and ‘underboomed the carbs’ of which O’Rourke’s

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[36] Meghan O’Rourke, *Sun in Days: Poems* (New York: W. W. Norton & Company, 2017), p. 53. Emphasis in original.

poem is the only use I can find). The poem is addressed to the illness in the style of an apostrophe, a figure of speech that addresses something that is absent. This has the effect of personifying the mystery illness, invoking its presence even as its aetiology eludes both the speaker and her doctor. In being addressed in the second person, the illness is given a presence as a coherent thing rather than a (more or less coherent) cluster of symptoms.

The first quoted line is neatly structured, with all the actions ordered by the verb 'went for'. But in the second quoted line, the order starts to break down; 'I pressed my lips to you' disturbs the initial logics of inclusion by moving from concrete action to a more abstract category. In the fifth line of the quotation, ampersands start replacing commas as a means of structuring the items, emphasising an increasingly urgent repetition. This repetition culminates in the doctor's '*Just take more* he urged & *more*'. It is not clear to the reader what the '*more* [...] & *more*' might refer to, as none of the items mentioned can be 'taken'. The formulation describes an accumulation; of actions, orders, or simply doses of medications that do not work. While the referent has been forgotten, the feeling of being addressed imperatively has stayed. The onus is on the speaker since the doctor has abdicated all responsibility. The omission in the text of whatever the doctor is telling her to take also suggests the presence of other omissions; that the list of treatment and strategies is too long and too difficult to be contained on the page.

Umberto Eco describes this as the essential oscillation of the list as a form: a movement between the desire for finiteness and the recognition that it is an illusion, or as he puts it, between '"everything included" and the poetics of the "etcetera"'.[37]

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[37] Umberto Eco, *The Infinity of Lists*, trans. by Alastair McEwen (London: MacLehose Press, 2012), p. 7.

The items on the lists are not organised in relation to each other chronologically, but simply placed in the past tense, ordering them together by the affects they have collectively produced: futility, exhaustion, desperation. This list is not about enumeration but about the impossibility of including and articulating the speaker's experiences. The overarching effect of the poem is an illusion of order that disintegrates the closer you inspect it, perhaps representing an experience of living with an increasingly unfamiliar body. The list in O'Rourke's poem is a version of the 'horizontal' lists as defined by McDonald, extending out 'toward disarray and infinitude' rather than hemming its items in.[38] Together with other actions taken in the poem, which also range from concrete to abstract (mentioning 'the acupuncturist'; 'I went after you with a sinking inside and medical mushrooms'; 'I plumbed you'; 'I waxed toward all that waned inside'), the poem is a literary list rather than a medical one, a list of disorder rather than of order.

The list in 'Idiopathic Illness' is not about creating order but about rendering visible the complex network of actors and actions involved in the speaker's experience of illness. As such, the list contracts what could have been a chronological story where each action is described in relation to the ones that come before and after it. Eva von Contzen describes how the list form makes the 'flow [of ordinary narration] come to a halt and opens up a narrative space that is a-sequential and a-temporal with respect to the rest of the narrative'.[39] Each item on the list is a process, already truncated by being described synecdochally, such as when the baking of the masticated pig's thyroid stands in for the whole process of procuring, preparing, baking, ingesting, and evaluating results over a longer period of time. The

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[38] McDonald.

[39] Eva von Contzen, 'The Limits of Narration: Lists and Literary History', *Style*, 50.3 (2016), 241–60 (p. 246).

text breaks out of the narrative flow to open a textual repository that can connect the many treatments by different professionals at different times. The poem uses the list to bring these processes together, some of which will have been synchronous, but most of which will have had different sequential statuses and temporal durations, to create a narrative space which is a-sequential and a-temporal. The different strategies seem to blend to become one long, continuous action, the constituent parts no longer fully differentiable. The names of treatments only indicate in the briefest of ways the travails and hard work they contain, but this very reduction eschews the description of pain or discomfort. Instead of being described, the discomfort of going through this process is reproduced formally, through the barrage of items that is too long for the reader to hold them all in their mind.

The lists that appear in contemporary feminist illness writing are frequently impossible to quote in full because the length is part of their point: relentless, repetitive, exhausting. Dodie Bellamy, for example, starts the essay ‘When the Sick Rule the World’ with a list of questions that takes up almost three full pages.[40] These questions are revealed to be ones the narrator encounters at an alternative provider after she has given up on—and been given up on by—traditional biomedicine. The overwhelming quantity of the questions is emphasised by a complete lack of punctuation. Lists that are so long can be difficult to read; as the narratologist Monika Fludernik observes, a long list challenges readers’ cognitive ability. As she writes, ‘one can remember and visualize a series of three of four things, but, with more items on the list, the effect soon turns from clarity to confusion as the reader is disconcerted by the number of details raining down on her or him’.[41] A longer list,

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[40] Dodie Bellamy, *When the Sick Rule the World* (South Pasadena: Semiotexte, 2015), pp. 25–27.
[41] Monika Fludernik, ‘Descriptive Lists and List Descriptions’, *Style*, 50.3 (2016), 309–26 (p. 316).

like the ones in Bellamy's and O'Rourke's texts, instead visualise feelings of exhaustion and overwhelm. The form of the list is intrinsically expandable and potentially infinite; as a form it suggests that the labour will never be finished.

In O'Rourke's poem, the list asks the reader to do significant work in charting out the (non-) relationships between the items, and thus reproduces feelings of exhaustion and confusion, producing an insight into the abject experience of living with an undiagnosed illness. The list serves as proof of the work the patient has had to do by herself, while the doctor's exhortation for the speaker to always do more reinforces the dynamic in which she has to take responsibility for her own treatment. Using the list, the poem visualises the effort it takes to be ill; not only does the speaker have to deal with pain and mental exhaustion (the poem describes the illness as being 'in my brain, inflaming it', how it 'slipped into each cell', and how the speaker feels like 'a body gone flame'), the speaker must also employ significant time, energy, and money taking charge of their treatment: researching it, bringing new suggestions to their doctor, seeking information from other patients online, and trying out and evaluating different treatment and management strategies.

In her 2022 memoir *The Invisible Kingdom*, O'Rourke describes how the difficulty of categorising her symptom created experiential confusion. As O'Rourke writes: 'because my unwellness did not take the form of a disease I understood, with a clear-cut list of symptoms and a course of treatment, even I at times interpreted it as a series of signs about my very existence'; a sign of moral rather than physical issues.[42] O'Rourke attempts, qua Charon, to write a story instead, thinking that 'if only [she] could figure out what the story was, like the child in a fantasy novel who

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[42] Meghan O'Rourke, *The Invisible Kingdom: Reimagining Chronic Illness* (New York: Riverhead Books, 2022), p. 6.

must discover her secret name, [she] could become [her]self again'.[43] She is looking for a plot-line as well as a diagnosis, two very different things which seem to meld into one; the right story (correct point of inception, the right symptoms) will lead to the correct designation and category. However, it turns out not to be so simple. For O'Rourke, as for Berkowitz, the attempts to render themselves legible in medical language and the medical literary form of the list fail for a very long time, because medical knowledge itself fails. For all the ostensible clarity and authority of the diagnostic list, it hides gaps in medical knowledge. And in many chronic illnesses, naming the condition can give access to support and insurance claims; but if there is no known effective treatment, the symptoms do not improve just because the 'secret name' of the diagnosis has been found.

The difference from illness memoirs such as Norman Cousins's *Anatomy of an Illness* can be seen in how texts like *Sun in Days* and *Sick* describe the investigative work of illness but refuse a happy ending in which the illness is diagnosed and cured. In O'Rourke's *Sun in Days*, in the poem 'A Note on Process' the speaker asks 'There is nothing sustaining about sickness / and because there is no end, there can be no "goal" / and because there is no goal there is // no process / : so what is there?'[44] *Sick* also ends with a rejection of the familiar ending. Like *Ask Me About My Uterus*, it ends with a repetition of the beginning, in *Sick* the car crash that opened the story. 'And then,' the epilogue begins, 'the car crash'.[45] 'And then', it continues, again resorting to a kind of list as its structure, 'this book'.[46] The epilogue carries on as an unstructured list that describes the time after her car crash without connecting individual sentences, such as in this extract:

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[43] O'Rourke, *The Invisible Kingdom*, p. 6.
[44] O'Rourke, *Sun in Days*, p. 77.
[45] Khakpour, p. 219.
[46] Khakpour, p. 219.

> I lost twenty pounds in two months.
> Not a day went by that I didn't cry violently for hours.
> Not a day went by where I didn't know where I was for hours.
> Not a day went by without those killer headaches.
> Not a day went by when I didn't go back to thoughts of suicide, real ones, bright and hot.
> I could not tell you how I walked the dog, how I ate, how anything happened.[47]

The loose list-form description ends with her in hospital, imagining different scenarios, and suggesting that the only possible structure is a non-ending: 'The story didn't end as I imagined so many times: in the end I would make it'.[48] Her writing about illness continues in the newsletter *Sicker/Sickest*, which as the title suggests emphasises that the experience of chronic illness cannot be neatly contained but rather continues outside the bounds of a single published text.

The lists can formally represent the affects of despair, overwhelm, and exhaustion which the teleological story arcs cannot. In addition to being a site of negotiating different kinds of medical knowledge, the form of the list also affords the representation of the experience of chronicity when order is broken down or the list's affordance of enumeration is pushed past a certain point. The difference to 'quest narratives' is not in the representation of investigative illness labour but in the results of this. Even though the narrators of the texts by O'Rourke, Norman, Ramey, and Khakpour achieve diagnoses that explain at least some of their symptoms, these are not placed as the 'end' of a process. The fact that these texts place much of the investigative labour in lists has the effect of eliding a chronological or causal relationship between the different acts of investigative labour. The lists thus express the experience of undertaking illness work on practical, formal, and affective levels.

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[47] Khakpour, p. 220.
[48] Khakpour, p. 224.

The lists thus represent the most explicitly advocacy-related functions *and* some of the most experimental, 'literary' aspects of the texts.

Life writing and the list

Ask Me About My Uterus is an example of how tangled the relation between health-related and literary aims can be in illness memoirs. The text is the culmination of the investigative labour the narrator has done on her illness to date; it delivers the results while documenting the difficulty of the process. In a way, then, she manages to turn a small portion of her *decommodified labour* back into paid work again, using the illness memoir as a commodity. By putting together alternative list of symptoms, treatments, and strategies that do not conform to mainstream medical knowledge, the memoir contests the dominance of medical lists as governing the truth about condition or health issues. Like the online forums and other groupings which form their non-literary equivalent, the lists included in memoirs can participate in the creation and sharing of information collected from people who are ill. They may save others the labour of having to try each strategy or elicit recognition among readers with similar chronic health issues. The changes they describe the texts as potentially facilitating are thus external to the narrator rather than internal, related to advocacy and the championing of ill persons as knowledge-creators on par with medical staff and researchers.

In addition to serving activist aims, the lists of investigative illness labour function as documentation of illness labour, serving as evidence of tenacity and hard work in the ill person. Being seen as a faker, malingerer, or someone who is lazy is something that frequently comes up in accounts of contested or less well-known illnesses. Elaine Scarry describes this as the paradox of pain:

> For the person in pain, so incontestably and unnegotiably present is it that "having pain" may come to be thought of as the most vibrant example of what it is to "have certainty, " while for the other person it is so elusive that "hearing about pain" may exist as the primary model of what it is "to have doubt." Thus pain comes unsharably into our midst as at once that which cannot be denied and that which cannot be confirmed.[49]

Having chronic pain or a contested illness is at the very bottom of the medical hierarchy of illnesses, as described by Grue.[50] This necessitates, or at least is felt to necessitate, an extra burden of proof on those who have contested chronic illnesses, convincing both doctors and readers that they really are ill. The list can function as one way to provide this proof; Huber, who lives with rheumatoid arthritis, an illness which is well-described in medical literature, but which does manifest in chronic pain, describes the list as a form of evidence which the ill person may mount against those who are suspicious. In *Pain Woman Takes Your Keys*, the narrator describes the reactions she gets when she tells people about her chronic illness:

> Well-meaning people who learn about my health problems are thrown into discomfort, and the acceptable response these days is to offer an easy (if slightly insulting) solution: 'Have you tried yoga? Have you tried turmeric? Have you tried meditation?' First I tried to reply to each of their suggestions. Then I felt my intelligence being questioned, because as a responsible person I would look into every possible solution. Then I thought maybe I'd write a paragraph listing everything I have tried, sort of a sick person's résumé.[51]

The passage documents common attitudes to illness as something that should and can be fixed, a model which does not suit chronic illness. If someone stays ill for a longer period, suspicion arises: is the ill person doing enough, are they trying hard enough? In encountering these reactions, Huber describes feeling belittled, like the people who suggest banal strategies for her to try are implying that she is not taking responsibility for her illness.

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[49] Scarry, p. 4.
[50] Grue, p. 10.
[51] Huber, p. 48.

In wanting to write a list of all the strategies she has tried, ‘sort of like a sick person’s résume’, Huber ties the patient role to the world of work and the neoliberal demands of having to constantly mark oneself as able. The resumé, a form associated with professional experience, is invoked to prove the ill person’s skills and ability. Huber satirises the need for this list by suggesting having it in her wallet, ready to pass around to anyone who questions her approach to her illness, almost as if it was a photo of a child or loved one. The image thus indicates that the purposes of the list of strategies are twofold; while the simile of a resumé suggests catering to external pressure, the action of keeping the list in the wallet and taking it out to show to acquaintances indicates that the ill person’s desire to be seen as responsible and able is equally important. In Huber’s text, the list remains hypothetical; but the idea of the list of strategies as ‘a sick person’s résume’ may be suggestive of the functions of the lists of this kind that appears so often in contemporary feminist illness writing. The image of the resume highlights a desire to ‘prove’ discipline, skill, or even ‘professionalism’ in the state of illness.

As Philippe Lejeune has argued, both lists and life-writing have their roots in the traditions of accounting, cataloguing, and other administration.[52] Looking at the origins of the diary, Lejeune argues that it is intimately tied up with ideas of personal accountancy, self-scrutiny, and spiritual stockkeeping. One of his examples is the religious diaries required from Catholic school girls in nineteenth-century France. These books ‘were laid out like account books. They use one page for each week and one line for each day with two columns, one marked ‘V’ for victories (over the devil) and the other marked ‘D’ for defeats, with the total at the bottom’.[53] Lejeune

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[52] Philippe Lejeune, *On Diary* (University of Hawaii Press, 2009).

[53] Lejeune, p. 51. Cf. contemporary equivalents such as apps used for learning new habits, counting calories and apps designed to help the user or recording their physical activities—these similarly afford accountancy on a day-to-day basis.

argues that the impetus towards moral evaluation continues in modern day diary-writing and life-writing. Even outside a religious context, as a record of daily actions, thoughts, and feelings, diary-writing tends towards passing judgment. Similarly, biography and autobiography often evaluate the life and person described. Both accountancy and life-writing ostensibly create a comprehensive and accurate record of an individual's life, whether in terms of their personal or financial history, but often advance a particular narrative. A biography may be written to defend someone in the public eye or bring to light previously unknown dark chapters, and autobiographies are often described as providing the ‘full story’, i.e., correcting the public record by providing an alternative narrative. Most kinds of life writing have an element of persuasion—as Sidonie Smith and Julia Watson write in their comprehensive review of life writing theory, ‘imaginative acts of remembering always intersect with such rhetorical acts as assertion, justification, judgment, conviction, and interrogation [...] life narrators address readers whom they want to persuade of their version of experience’.[54]

When it comes to illness writing, a genre which G. Thomas Couser describes as helping bring about the rise of memoirs written by people who are not famous otherwise, the purpose is often to raise awareness or share information about the experience of a particular condition.[55] Norman’s agenda with *Ask Me About My Uterus: A Quest to Make Doctors Believe Women’s Pain* is set out clearly in the subtitle. She wants to use her personal story to raise awareness of endometriosis as a debilitating illness and how the treatment of endometriosis exemplifies broader issues of structural misogyny within the medical profession and medical research. As

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[54] Sidonie Smith and Julia Watson, *Reading Autobiography: A Guide for Interpreting Life Narratives, Second Edition* (University of Minnesota Press, 2010), p. 7.

[55] Couser.

such, the text's extensive scholarly apparatus—which includes other forms of lists: indexes, notes, suggested reading—establishes patient expertise, providing evidence for 'the work [she]'d done to become an expert in [her] own body'.[56]

Self-representation is always part of this; as disability and illness writer Christina Crosby explicitly tells the reader in the memoir *A Body, Undone: Living on After Great Pain* (2016): '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'.[57] Just like medical guidelines and lists of questions can signal thoroughness, patients' lists of the actions they have taken can be ways of proving their own investment in managing their illness, or documentation of the knowledge they have built up. As described earlier, this is a way of claiming legitimacy in the face of prejudice and packaging it in a language of value that society already recognises. The need to 'prove' these qualities speaks to the marginalisation of the ill subject. Against a political backdrop in which people who are chronically ill are typically described as a net cost to the economy, writing a personal story can be a way to provide a more nuanced story that humanises and asserts the value of the ill subject.

Lists can be instruments of ordering and discipline; as media historian Liam Cole Young describes, they are a means by which we can 'glimpse the techniques and technologies by which human societies administer, police and imagine themselves'.[58] In O'Rourke's poem, the speaker is laying out her evidence for her discipline and tenacity in trying to cure herself, perhaps to counter societal

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[56] Norman, p. 247.

[57] Christina Crosby, *A Body, Undone: Living on After Great Pain* (New York: New York University Press, 2016), p. 19.

[58] Liam Cole Young, *List Cultures: Knowledge and Poetics from Mesopotamia to Buzzfeed* (Amsterdam: Amsterdam University Press, 2017), p. 10.

judgments that she has not done enough or that she is not really ill. At the end of the poem, the speaker makes a claim for the strength of her will, even though this entails rejecting her body: ‘What can be said? I came w/o a warranty. / Stripped of me—or me-ish-ness—/ I was a will in a subpar body’.[59] She demonstrates the toll that having to take responsibility for trying to get better has on her, but also locates the fault in the body which escapes controllability. Using the metaphor of a body as a manufactured product issued without a warranty, O’Rourke’s poem critiques the lack of a public security net in the US; a system in which the lack of social pooling of risk through welfare, national insurance, and social security measures constructs illness as an individual problem. The lists in O’Rourke’s poem and *Ask Me About My Uterus* show the speakers as participating in, and being regulated by, the lists of treatments and strategies they are employing to achieve diagnosis and to live with less pain. We can see this documentation of ‘discipline’ in the lists of strategies the authors have undertaken, but we can also see it in lists that push against this narrative of the ‘good’ patient. As instruments of control and discipline (not least within medicine), lists afford the organization of the individual into a ‘good patient’.

But lists also afford a means through which to break with these norms. Khakpour’s *Sick* includes lists illustrating the hard work associated with illness, and describes her ‘health,’ ‘wellness,’ and ‘healing’ as ‘full-time job[s]’.[60] But the text also problematizes the idea of the ‘good,’ virtuous patient who is ‘working’ on their health. The text recounts many examples of Khakpour doing the ‘wrong’ thing as a patient, and while the memoir generally follows a jumbled timeline, the interlude ‘On Being a Bad Sick Person’ at the end of the text makes a point of reiterating all

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[59] O’Rourke, *Sun in Days*, p. 54.
[60] Khakpour, pp. 196; 194; 147.

the points in the story at which the narrator is being a ‘bad’ patient. This list enumerates her lack of compliance with medical instructions:

> With Lyme disease, certain diets are recommended. It’s been long believed that sugar, dairy, and gluten can exacerbate Lyme symptoms. A paleo or ketogenic diet was often recommended; another diet called ‘Bulletproof’ required I drink butter coffee for the first half of my day. I rebelled from all these at some point, being a carb addict for one thing. [...] I ate bread. I ate sweets. I ate junk food and dairy. Fries with mayo have probably been my favorite food since I can remember. And I went further with toxins: I drank, I smoked, I even occasionally did drugs.[61]

By repeating these actions, the narrator emphasises her refusal to submit fully to the role of the ‘good’ patient. Starting out with the ‘lighter’ offence of failing to stick to specific diets, the transgressions become more serious. As the length of the sentences increase, so do her deviations from the recommendations, culminating in the acts of drinking, smoking, and taking drugs.

The inclusion of being a ‘carb addict’ and ‘taking drugs’ invoke medical concepts but removes them from their context. The narrator trivialises addiction (more serious versions of which she suffers from at points in the text) to humorously characterise her diet. The action of ‘taking drugs’, which could describe a sanctioned medical behaviour, is subverted by the context of the list indicating that it is referring to recreational drug use, emphasising the way in which the list of transgressions is a foil to the lists attesting to discipline and responsible behaviour. However, it is not simply a medical list she is working against; diets like ‘Bulletproof’ and paleo are not medically supported, demonstrating that the demands of the patient are societally induces as much as medically prescribed, as also shown by Huber’s example.

Confessing these transgressions point back to the memoir as a form of accountancy, giving evidence on both sides of the equation, similarly to the Catholic

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[61] Khakpour, p. 201.

school girls in the diaries analysed by Lejeune. The narrator accepts part responsibility for her bad health, not only her periods of remission:

> Another part of it is the thrill of the sick person making herself sicker. If you know a part of you is always dying, taking charge of that dying has a feeling of empowerment. My body goes against me often, so what if I put it through that myself? […] In some ways, I keep myself sick.[62]

While her admission of 'keep[ing] [her]self sick' by not following instructions can be seen as playing into the ideal of the patient whose only way to health is hard work, Khakpour subverts the normal usage of 'empowerment' in relation to the proactive patient role. Emphasising that agency and empowerment can also be found in disobeying doctors' orders, Khakpour underscores the importance of a sense of autonomy. The narrator makes repeated gestures to narrative transparency, even if they often also testify to the text being unbalanced in its representation of events. Towards the end of the text, which extensively describe a series of heterosexual relationships, the narrator mentions that she had relationships with women in the period described by the memoir, even if they are not included. In a parenthesis, she writes, 'I tend not to dwell on bisexuality in these pages, but I've identified as queer since the mid-'90s. Because I am afforded heterosexual privilege in dating men so often, I tend not to rush to mark that box. […] But I question that omission; to leave that out would be disengenuous [sic] too'.[63] *Sick* thus metatextually reflects on its own status as a truthful object, concluding that presenting both compliance and rebellion is necessary to achieving some objectivity in its account of illness.

There is, however, a difference in how much space the items are given in the narrative. Some are described in detail while others are cursorily mentioned. While some of the investigative labour related to experimenting with new treatments is

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[62] Khakpour, p. 204.
[63] Khakpour, p. 214.

described at length in the text (for example the bee sting therapy Khakpour's narrator receives in Santa Fe), the lists in the text often contain the items which would be too uninteresting to describe in detail, but which nonetheless must be mentioned in order to encompass the full demands of the experience of being ill. As in the texts by O'Rourke and Norman, the lists of failed strategies function as textual repositories for actions not expanded due to reasons of writerly or readerly exhaustion.

Lists and labour

In addition to being a powerful metaphor due to its connotations to social legitimacy and particular affective dimensions, *work* is also an activity and a form of social organisation. Levine describes labour as a 'social rhythm', defined as such through its regular repetition over time.[64] The investigative labour related to chronic illness does not on the outset look like a rhythm. Each treatment or strategy carries the hope that it may be the last; each undertaking could be the one that leads to radical change or cure. In anticipation, each item looks like a singular event. It is only in retrospect, and particularly through the retrospective mode of life-writing, that the many distinct events add up to a social rhythm: the repetition of tiresome efforts. In other words, organised thus it comes to resemble (precarious) labour. The investigative labour of illness is thus similar to work because of its experiential dimensions (difficult, effortful, time-consuming, skilled, necessary, exploitative) but also because of its pattern of recurrence. Writers describe the investigative labour as work not only to prove themselves to someone else—a doctor, the reader—but because the two forms resemble each other.

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[64] Levine, 'Forms, Literary and Social', p. 78.

But the repetitive nature of labour, including the labour related to illness, also presents challenges to the mode of the memoir, for which the affordances are to summarise, evaluate, and filter: to include the significant while editing out the unsignificant. Boyer acknowledges this in an observation about the necessity of non-teleological form to illness writing and its representation of labour in *The Undying*. A teleological and dramatic narrative about 'death' is exciting, Boyer writes; it 'has a plot and a readership'.[65] On the other hand, 'exhaustion', the subject which links the ill person to class struggle, 'is boring, requires no genius, is democratic in practice, lack fans. In this, it's like experimental literature'.[66] Illness labour, like other types of labour, is boring in its repetition, necessitating literary forms which can represent this quality.

Boyer again makes this link explicit when comparing the daily care work of illness to domestic labour, and its formal consequences:

> Doing the dishes is not like freedom. Freedom is whatever we notice because it isn't like doing the dishes. The ordinary is ordinary because it ordinarily repeats: *taking care* lacks freedom's entertainments and its exceptions. // For any author of doing the dishes, the best part of the story would be the story of missing out on everything else while the dishes are being done. […] it would be easy for any of those accounts of doing the dishes to miss what is important about doing the dishes, which is that it is not interesting or remarkable work in itself, but that it is the work on which everything else depends. // An ongoing necessity like dirty dishes needing to be done doesn't produce narrative. It produces quantities, like how many dishes were washed. It produces temporal measurements, like how much time was spent washing them and when. Narratives end. Quantities, hours and dishes don't.[67]

In chronic illness, the labour of managing and investigating the illness does not end either. Like the dirty dishes, the investigative and management labour of illness produce quantities rather than arcs: actions that simply follow each other, but where the order they happen in does not really matter, as is clear by the non-chronology of

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[65] Boyer, *The Undying*, p. 245.
[66] Boyer, *The Undying*, p. 245.
[67] Boyer, *The Undying*, p. 107.

the lists. As Boyer points out, the point about the labour of managing symptoms of chronic illness is that it exceeds the boundaries of the illness text. It also does not conform to the form of the teleological illness narrative, in which each action is significant because it contributed to leading the character to the endpoint they arrive at and tell the story from. This is also how Christina Crosby describes the relationship between story structure and the experience of living with severe disability after a bicycle crash. She describes living with her condition as being 'repeatedly, daily, relentlessly, and wearingly horrified by the elsewhere of spinal cord injury'.[68]

Crosby observes that most of the illness and disability memoirs she read after being injured follow the mode of a realist novel: 'the narrative develops chronologically after the advent of incapacity, all the while implicitly articulating events into a consequential order'.[69] She writes that her own experience is much closer to the narrative model of a horror story, which is about intensifying affect rather than the order or significance of events in relation to each other. 'The tumultuous end leaves unanswered all causal questions, which actually never had purchase in the story, anyway. In a horror story, *how* the characters and events of the story are ordered and discussed collapses into the *what* of those events that gathers affective force'.[70] It is not the content of the horror story that she recognises, but instead a narrative mode which eschews causality in favour of the representation of an overwhelming affect. The horror story, in her account, affords the accumulation of emotion in a way that mirrors her experience of living with injury, a story which is not about how one thing leads to another, but about how strain builds over time.

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[68] Crosby, p. 192.
[69] Crosby, p. 188.
[70] Crosby, p. 191.

Borrowing Boyer's observation, I argue that the lists addressed in this chapter affords the representation of 'quantities'. Authors use the form to express the burden of illness labour and the experience that is very often connected to it: a sense of despair and futility because most of the efforts lead nowhere. Insisting on the necessity of making space for this labour is integral to the political power of the texts. This recalls Weeks' description how the *Wages for Housework* movement drew attention to reproductive and domestic labour as work to insist 'on its demystification, de-romanticization, de-privatization, de-individualization, and of course, de-gendering'.[71] The concept of 'demystification' is particularly salient to the example of contemporary feminist illness writing and its depictions of illness labour. There is political power in naming the tasks because this renders them visible, which is even more significant when it comes to the investigative labour related to 'mysterious' illnesses. The texts put a face and a name to the actions that demonstrate living with contested illness as an active and demanding process. Just like living with more well-known and acute illnesses—and like living without illness, as someone whose contribution to society is valued.

As described in previous chapters, invoking the vocabulary of work is a way of politicising a subject. Describing an ill person as a type of worker is a way to claim legitimacy and belonging to a political grouping. The lists of illness labour demystifies and deromanticizes attempts at managing and alleviating symptoms, forming a basis of visibility on which more overt resistance can be built. Read as a therapeutic document, the illness memoir can be seen as participating in neoliberal ideals according to which the challenges posed by illness should be addressed by the individual's own personal efforts. However, focusing instead on the knowledge

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[71] Souvlis and Weeks.

collectively produced by the lists, it becomes possible to draw conclusions across works about how contemporary political and economic factors shape the daily experience of illness. Lauren Berlant uses the concept of *slow death* to describe how some populations' lives and health are subject to managed attrition through political, economic, and environmental factors, namely neoliberal austerity measures. She describes how, 'in the scene of slow death, a condition of being worn out by the activity of reproducing life, *agency can be an activity of maintenance, not making*'.[72] Illness labour can be such an act of maintenance, easily escaping view among ostensibly more impressive feats. But survival and navigation of everyday life can also be an achievement and is, importantly, an experience many share for different reasons.

It is significant that it is so often patient work that is being *listed* in these texts. This suggests that patient work occupies an uneasy place in illness narratives more generally as well as in the experiences of chronic illness. The long descriptions of tasks undertaken and money and time spent in the pursuit of a remedy both play into and conflict with the arguments made by the texts. The lists testify to a 'professionalisation' of the patient role which is also reflected in Huber's description of the list of treatments undertaken as 'a sick person's résumé'. Summarising the contribution of a special issue of *Style* on the literary history of lists, von Contzen argues that 'lists are at potentially precarious moments of literary history and hence indicative of breaks, ruptures, paradigm shifts, and new negotiations emerging at the interface of form and context'.[73] As borderlands of a sort, where the contents of the illness narrative are being negotiated—what goes in and what does not—lists can

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[72] Lauren Berlant, 'Slow Death (Sovereignty, Obesity, Lateral Agency)', *Critical Inquiry*, 33.4 (2007), 754–80 (p. 759).
[73] von Contzen, p. 242.

draw attention to the structures that are being upheld or negated, charting the individual text's relationship to other narratives and the genre of the illness memoir. As such, lists help express something that cannot be contained in the surrounding prose: the sustained, repetitive, and active process of being ill and seeking to manage a condition.

I have argued that one conflict being negotiated in the lists is that described by Norman and Ramey, of the onus of the active patient role in chronic illness. Patients are expected to project-manage their own illness but can easily be seen to overstep their domains, actions for which they may be punished by doctors. When it comes to investigative or diagnostic work, many of those who are ill (and particularly women and/or people of colour) are being dismissed and the work they have done researching their conditions is not listened to. Much of this speaks to medical neglect; it is clear from these texts that many people who are ill are being mistreated and misdiagnosed. There is a growing awareness of this also within the medical profession; as a doctor has written recently, people with so-called functional disorders (such as fibromyalgia as described by Berkowitz, ME as described by Hattrick in Chapter 1, and sometimes Multiple Chemical Sensitivity as described by Dodie Bellamy) 'are patients whom medicine has failed more than almost any other group'.[74] Within the daily labour of illness work, there is an important distinction to be made between the tasks undertaken by those who are ill, as described in Chapter 2, and the extraordinary proactive work required from people who are ill due to insufficient or failing healthcare provision, described in this chapter. In contemporary feminist illness writing, it is often work undertaken when the medical

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[74] Richard Smith, '"Functional Disorders": One of Medicine's Biggest Failures', *BMJ*, 380 (2023), 221–22 (p. 221) <https://doi.org/10.1136/bmj.p221>.

system fails that is listed, something that suggests the uneasy status of this labour undertaken on the margins of medical knowledge and patient status.

A list is in no way a stable structure or entity; as is already made clear by the examples in this chapter, there are many types of list and many ways in which authors play with this form. The list of failed strategies serves a different purpose to the list of goals or the to-do list. It is also different from the list of medical symptoms or guidelines; whereas the medical list of symptoms is an aggregation of patient data, aiming to be as objective and general as possible, the list of failed strategies is profoundly personal in content, describing the individual's efforts within and without the boundaries of medical knowledge. Formally, the lists can be read as an example of a non-teleological narrative form which in many ways functions as microcosm of the texts they're found in: texts which emphasis the unending, repetitive, exhaustive labour of illness. The lists analysed in this chapter are examples of a non-teleological form, but they are also some of the places in contemporary illness writing where the burden of labour related to illness is made most clear. In offering a more in-depth 'case study' of this form, I show how a form which is closely linked to technologies of self-management and control also offers options for resistance against this ideal.

This chapter has opened a discussion of the objectives as described in contemporary feminist illness texts. Norman, Ramey, O'Rourke, and Khakpour all gesture towards the information-sharing purposes of the texts, and their potential in raising awareness of the conditions they suffer from, among healthcare staff and others with similar symptoms, in addition to the literary and formal ambitions of developing new narrative structures which more accurately express the experience of chronicity. The next chapter looks at a different formulation of which changes illness writers and illness writing can bring about. Chapter 4 will look at 'access work'.

This is labour which is exacerbated by the illness writer obtaining more success and assimilation into the mainstream, a position which in turn facilitates new forms of activism. Access work reaches even further into workplaces and work practises, and the forms it takes consequently come from the professional, office-based world as well: e-mails, reports, pdf guides. Rather than the collisions with medical professionals and alternative providers as described in this chapter, the next chapter turns to collisions with organisational workplaces in the arts world and in literary publishing.

Chapter 4: Access Work, Institutional Critique, and the Illness Writer

> Sent October 14, 2021, 4:01 PM
> *Subject line: ableism in the [redacted] residency*
> dear d— and t—,
> i'm writing because it's been brought to my attention that your institution's practices while working with the residents were not supportive of their accessibility requirements and, worse, enacted the very ableist bullshit that the residency claimed to be critical against. […] disability access is a practice, not a virtue signal for press releases or funding applications. from what i've been told, you demanded last-minute work, decisions, and/or planning from the residents—which went against their accessibility riders and capacities. i experienced this very thing during the process of getting the call ready to go online with you, which begs the question of why the institution's practices require stressed and rushed labor from its staff that is then passed off to be borne by its residents—isn't this sort of overwork and capitalist exploitation of labor the very thing disability access pushes back against?
> […]
> sincerely,
> Johanna Hedva[1]

Johanna Hedva sent this e-mail to an arts residency programme for which they had been on the panel selecting the participants. As described in the e-mail, Hedva had been contacted by participants who experienced their access needs not being accommodated by the organisers. As a known chronic illness and disability advocate whose name had been associated with the residency, Hedva in return raised the issue with the organisers by sending the e-mail. And the conflict did not stop there; Hedva published the e-mail in the above redacted form, along with eight other 'angry e-mails' sent to other arts organisations, in the essay 'Why It's Taking So Long' (2022).[2]

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[1] Johanna Hedva, 'Why It's Taking So Long', *Topical Cream*, 13 March 2022 <https://topicalcream.org/features/why-its-taking-so-long/> [accessed 1 December 2022].

[2] Hedva, 'Why It's Taking So Long'.

The e-mail addresses a number of key concepts: ableism, institutional practices, disability access, and 'overwork and capitalist exploitation of labor'. Hedva is describing a tension between the value the residency claimed to espouse—disability access—and the actual practices and work environment created by the institution, relying on 'last-minute work, decisions, and/or planning', 'stressed and rushed labor', and lack of respect for participants' accessibility requirements. Together with the eight other reproduced e-mails, as well as Hedva's reflections on their own experiences, 'Why It's Taking So Long' paints a picture of the contemporary literary and arts world as spaces in which illness and disability have become fashionable themes, but chronically ill and disabled writers and artists are barred from fully participating due to a lack of accommodations.

The e-mail cited above speaks to the concept of *access work*: the fourth type of labour that I argue is exemplary of contemporary feminist illness writing's engagement with the concept of work. Access work is the labour which must be undertaken to make a given social space or environment more accessible. Access work—advocacy, sending e-mails, sharing knowledge, and the 'work of complaint' (Sara Ahmed)—in some respects resemble and overlap with the patient work described in Chapter 2 and the investigative illness labour described in Chapter 3. But access work has public and activist dimensions that are different to these other forms of labour: it intervenes directly into organisations and workplaces and seeks to make lasting changes. Although most chronically ill disabled people undertake access work as a daily occurrence, Hedva describes how the status of becoming a well-known illness and disability advocate exacerbated this work, leading to situations like the one giving rise to the e-mail cited in the introduction, in which Hedva was contacted by others to advocate on their behalf.

‘Why It’s Taking So Long’ thus reflects a significant turning point in the status of contemporary illness writing. Writing about chronic illness and disability is no longer posited on the outer margins but is now given space by mainstream publishers and institutions. But the move slightly closer towards the centre has been uneasy, as Hedva’s essay demonstrates. Not due to their subject matter or a lack of interest in the experience of illness, but rather because of the work environments in which artworks, talks, and texts are produced. As the author of one of the most widely read pieces of illness writing, ‘Sick Woman Theory’ (2016), Hedva experienced the surge in interest first hand, receiving many more invitations to speak, exhibit and publish; but, as they describe, typically from organisers who did not understand what it meant to accommodate a chronically ill and disabled artist. This necessitated a whole new type of labour. ‘I found myself giving Ableism 101 lectures over and over and it made me want to scream,’ Hedva writes:

> In reality it’s meant that I spend most of my time not on my actual work, but writing emails that explain, say, why live captioning or ASL are important to have at lectures, or an all-gender restroom is preferred, or the building needs to have a ramp and an elevator, and then getting into email fights about it.[3]

This labour is closely related to the changed status of illness writing and the ‘illness writer’ as a more commodified product: an additional burden but also an opportunity for impact.

But impact does not come easily, as Hedva’s description of getting into ‘email fights’ intimates. Even within institutions whose work focuses on diversity and inclusion, changing work practices so they are accessible to those with different capacities seems to represent something almost unthinkable. Arts institutions often like to think of themselves as opposed to capitalist ideology, but at the same time

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[3] Hedva, ‘Why It’s Taking So Long’.

they typically represent precarious and exploitative workplaces.[4] The fact that the essay is directed at organisations within the art world also underscores the fact that the two worlds intersect when it comes to the careers of contemporary illness writers; literary texts are not only produced within the literary landscape but are engendered by the practices of the art world. Hedva's essay presses on two significant questions: what is the relationship between literary and artistic work which seeks to break down the ideals of capacity and able-bodiedness, and their capitalist networks of production? And what might be the material objectives of contemporary feminist illness writing, if not to intervene into the workplaces in which they are produced and make them more accessible?

Chapter 1 described how contemporary feminist illness writers draw attention to their process of writing as part of making illness writing visible as a form of *work*. This chapter broadens the examination of this subject in contemporary texts by analysing how writers reflect on, and intervene into, the extended network of literary and artistic production. Whereas the first chapter described how chronic illness shapes the experience of creative work on an individual level, this chapter thus describes how it impacts the position of the creative worker in the current cultural economy. Moreover, in addition to claiming the symbolical status of precarious workers as described in Chapter 2, this chapter examines how the writers do so in material terms: exploring their own identities, power, and rights as workers in institutional and organisational workplaces.

In the first section of this chapter, I look at Hedva as a writer whose trajectory is exemplary of the development of the status of illness writing between

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[4] Rosalind Gill and Andy Pratt, 'In the Social Factory?: Immaterial Labour, Precariousness and Cultural Work', *Theory, Culture & Society*, 25.7–8 (2008), 1–30; Angela McRobbie, *Be Creative: Making a Living in the New Culture Industries* (Cambridge: Polity, 2016).

2015 and 2022. I use Hedva's own story of this development in 'Why It's Taking So Long' to analyse the changed formulation of the aims of the literary illness text as grounded in the concepts of 'access' and 'access work'. I argue that access work is not just a theme, but a concept encapsulating why the texts matter and the intended effect they will have in the world. As such, access work names the desired process started by the texts, creating an alternative to a concept like Arthur Frank's *dyadic bodies* that conceptualises the effect of illness writing on readers and the wider society. The second section looks at the concept of *access work* in texts by contemporary feminist illness writers including Hedva, Mia Mingus, and Leah Lakshmi Piepzna-Samarasinha. I look at two examples of 'access documents': Hedva's 'access rider', like the ones mentioned in the e-mail cited above, and an 'accessibility guide' by Lazard. I place the authors' use of these forms in relation to the art historical concept of *institutional critique*, used about artworks which aim to change art institutions from within, and in which the administrative work and bureaucratic processes become part of the artworks themselves. In the third section, I return to 'Why It's Taking So Long', focusing on the use of e-mails as a form with affordances to documentation, exchange, and reproducibility. I build on Tanya Titchkovsky's conceptualisation of the bureaucratic as a site of particular use for understanding the negotiation of 'access'. I also return to the question of the illness writer's changing role in the cultural economy, between the margins and the centre. In the final section of the Chapter, I tie together the concerns of the previous sections, arguing that the necessity of undertaking access work, the reception of illness writers in arts institutions, and the changing status of illness writing have all shaped the new literary forms seen in contemporary feminist illness writing.

In this chapter, I argue that figuring the illness and disability writer as a worker whose workplace must be accessible has consequences for a new formulation of the material objectives of illness writing: advancing disability access and justice. The use of the bureaucratic technologies and forms, and the objectives of disability access which can be advanced within these, in turn engender new forms of illness texts. These form alternatives to the illness memoir. Texts including 'Why It's Taking So Long' and 'Hedva's Disability Rider', as well as work by Lazard and Piepzna-Samarasinha are structured differently to the illness memoirs which are normally the subjects of literary analyses of illness writing, and which I have focused on in previous chapters. These newer texts appropriate, include, and exploit the affordances of the textual forms of the institutional workplace—the e-mail, the accessibility guide, and the artist's 'rider'—and may look more like a set of instructions than any kind of 'narrative'. But I argue for including them on an equal basis to other illness writing, especially as they chart the practice of 'access work' and the negotiation of a new positionality of the illness writer. They represent the starkest examples of the use of non-teleological forms in contemporary feminist illness writing and chart the newest ways in which illness writing is re-inventing its forms and objectives.

'Access' and 'access work'

Before publishing 'Sick Woman Theory', Hedva had been working as a writer and artist for a decade at small institutions and in the academy. Hedva first gave the text as a talk entitled 'My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want it to Matter Politically' on 7th October, 2015. The talk had been scheduled to take place at a small venue, The Women's Center for Creative

Work, but in the run-up to the event, over 700 people tried to sign up.[5] This prompted the organisers to move the event to a bigger venue, the still relatively small Los Angeles art gallery Human Resources, and arrange for live-streaming and video recording. Both the organisers and Hedva started the event by saying how surprised they were to see such a large turnout at a talk about the chronically ill female body. Hedva said:

> My original plan for this evening was for a much more intimate affair. I had imagined that maybe five or six of my fellow sick women friends and I would sit around on big pillows and dip our feet in epsom salt tubs, sharing stories about how much our male doctors invalidate us.[6]

While Hedva's image of the intimate therapeutic space is perhaps exaggerated for comic effect, the contrast between the perception of the topic as marginal and its actual success is indicative of this being a turning point for feminist illness writing. From the point of the talk and until the publication of the text as 'Sick Woman Theory', a 90-minute video recording circulated, that as of November 2019 had over 100,000 views.

Hedva's talk in 2015 and the subsequent publication of 'Sick Woman Theory' now marks a shift in contemporary feminist illness writing. The popularity of the initial talk, video recording, and publication proved that there was an audience for political illness writing. Writing three months later, the poet Anne Boyer describes how Hedva had articulated something that had been simmering under the surface. Particularly, Boyer argues, a movement located in Los Angeles, where earlier that same year Beth Murray, Amy Berkowitz, and Dodie Bellamy had all published literary works in which personal experience of illness was contextualised

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[5] See the original Facebook event, available at: https://www.facebook.com/events/932558720151104/?active_tab=about

[6] *My Body Is a Prison of Pain so I Want to Leave It Like a Mystic But I Also Love It & Want It to Matter Politically*.

within post-financial crisis austerity and the global environmental crisis. As Boyer writes,

> There was this feeling that a collective project of important thinking was coming together—by that force that feels like beneficial accident but is actually always the force of history—about the sick, pained, feminized body in current conditions—that body (our bodies) so often made sick by those current conditions.[7]

By capturing a certain mood that was of the time and of the location, Boyer writes, Hedva's talk provided a focal point around which a particular conversation could coagulate. Eight years later, this assessment is hard to contest: the publication of works dealing specifically with the 'sick, pained, feminized body in current conditions' has become a global anglophone phenomenon, extending into magazines, exhibitions, conferences and events, special issues, and the publication of literary works on the theme of illness, disability politics, and care.[8]

However, while Hedva experienced being given a host of new opportunities, they were only able to accept few of these. Out of all the events and exhibitions they were invited to contribute to in the six years following the publication of 'Sick Woman Theory', only one event had comprehensive accessibility. As Hedva describes in 'Why It's Taking So Long', they simply were not able to *access* them without doing significant amounts of labour. It is worth examining the concepts of access and access work, which have been theorised in disability studies, before returning to the ways in which Hedva and other contemporary feminist illness writers use these concepts in their recent texts.

Access is a much-used yet slippery concept in contemporary illness and disability theory. In the US, the Americans with Disabilities Act of 1990 (ADA)

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[7] Anne Boyer, 'Tender Theory', *The Poetry Foundation*, 2016 <https://www.poetryfoundation.org/harriet/2016/01/tender-theory-> [accessed 18 September 2019].

[8] See the introduction for more details.

made basic accessibility and ‘reasonable accommodations’ a right.[9] The ADA aims to ensure that individuals with disabilities have equal opportunities and equal access to services and facilities as those without disabilities. This piece of legislation was rooted in the workplace and in workplace accommodations; it held employers responsible for creating an accessible environment for workers with the purpose of supporting more people into employment. In the UK, the Disability Discrimination Act 1995 and later the more comprehensive Equality Act of 2010 have prohibited discrimination on the basis of disability, as well as other protected characteristics such as age, gender, race, religion, and sexual orientation. Like the ADA, the Equality Act of 2010 requires employers to make ‘reasonable adjustments’ to ensure that people with disabilities are not disadvantaged in the workplace, with a view to supporting more disabled people into employment.[10] These pieces of legislation, however, have been criticised for being enforced through the efforts of those who are disabled.[11] In practice, those who need the accommodations are responsible for applying for them. In the US, this often involves filing lawsuits against businesses and organisations that do not comply.

As Hedva points out in the examples quoted above, access can include elements directly connected to illness and disability like sign language interpretation or live captioning for those who are d/Deaf or hard of hearing and ramps for people in wheelchairs. However, as used in the chronic illness and disability community, it can also include aspects such as all-gender toilets, childcare, warmth, quiet spaces,

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[9] U.S. Department of Justice, *Americans with Disabilities Act of 1990, As Amended* <https://www.ada.gov/law-and-regs/ada/> [accessed 14 May 2023].

[10] Government Equalities Office and Equalities and Human Rights Commission, ‘Equality Act 2010: Guidance’, *GOV.UK*, 2015 <https://www.gov.uk/guidance/equality-act-2010-guidance> [accessed 3 June 2023].

[11] Desiree Valentine, ‘Access and Relationality’, *Blog of the APA*, 2021 <https://blog.apaonline.org/2021/11/08/access-and-relationality/> [accessed 8 May 2023]; Aimi Hamraie, ‘Beyond Accommodation: Disability, Feminist Philosophy, and the Design of Everyday Academic Life’, *PhiloSOPHIA*, 6.2 (2016), 259–71.

and free food that support other marginalised populations to participate.[12] The breadth of the term is both its strength and weakness; as Titchkovsky writes, ‘sometimes access comes up as a question, at other times as an answer, and at still other times it doesn’t come up at all’.[13]

Bess Williams, in *Keywords for Disability Studies* (2015), describes how the term is used both to ‘characterize the relationship between the disabled body and the physical environment’ as well as about efforts to ‘reform architecture and technology to address diverse human abilities’.[14] Access can be a lens through which to analyse how, for example, built environments, social spaces, and organisations invite some people in while excluding others, often simply by assuming a particular ‘normal’ user. Tanya Titchkovsky takes the use of access as a critical term one step further by describing it as a ‘questioning orientation’ at the heart of critical disability studies:

> Exploring the meanings of access is, fundamentally, the exploration of the meaning of our lives together—who is together with whom, how, where, when, and why? Once we recognise this, we can begin to regard disability as a valuable interpretive space for denaturalizing our existence and complicating singular or totalizing ways of making meaning as bodied beings.[15]

Disability access, as Hedva also argues in the e-mail, is a complex practice which cannot be reduced to a theme. It is not enough for arts organisations to say they welcome people with disabilities; they must be able to accommodate different abilities, which means possibly changing fundamental aspects of their organisation. This can include more obvious dimensions, such as their physical layout, but also things such as their work timelines and decision-making processes. There is no such

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[12] Piepzna-Samarasinha, *Care Work*.

[13] Tanya Titchkosky, *The Question of Access: Disability, Space, Meaning*, 2nd edition (Toronto: University of Toronto Press, 2011), p. 3.

[14] Bess Williams, ‘Access’, in *Keywords for Disability Studies*, ed. by Rachel Adams, Benjamin Reiss, and David Serlin (NYU Press, 2015), pp. 14–17 (p. 14).

[15] Titchkosky, p. 6.

thing as ‘full’ or ‘achieved’ access. Elements that make an event or an artwork accessible to one person make it inaccessible to someone else. Someone who is bedbound may only be able to access an event if it is online, but online events can be inaccessible to those who cannot look at screens or have unstable internet connections. As a result, many writers avoid defining the term or provide descriptions that are deliberately vague. Stacey Milbern, for example, describes ‘collective access’ as ‘asking after one another and making sure folks had what they need’.[16]

In a widely cited 2011 blog post, Mia Mingus similarly describes what she calls ‘access intimacy’ as ‘that elusive, hard to describe feeling when someone else “gets” your access needs’.[17] Mingus’ concept focuses on cultivating empathy; it removes the onus on the disabled or ill person to communicate their needs and instead argues that care is when the network of people surrounding them use their energy to anticipate their needs. ‘The power of access intimacy,’ she writes, ‘is that it reorients our approach from one where disabled people are expected to squeeze into able bodied people’s world, and instead *calls upon able bodied people to inhabit our world*’.[18] While the version of the essay from 2011 veers almost into an erotics of access—Mingus describes sometimes mistaking access for sex—a 2017 rewriting of the text shifts towards a more economic analysis. Mingus invokes the language of labour, arguing that access intimacy is ‘shared work by all people involved, it is no longer the familiar story of disabled people having to do *all the work* to build the

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[16] Stacey Milbern, qtd. as epigraph to Piepzna-Samarasinha, *Care Work*.

[17] Mia Mingus, ‘Access Intimacy: The Missing Link’, *Leaving Evidence*, 2011 <https://leavingevidence.wordpress.com/2011/05/05/access-intimacy-the-missing-link/> [accessed 1 December 2022].

[18] Mia Mingus, ‘Access Intimacy, Interdependence and Disability Justice’, *Leaving Evidence*, 2017 <https://leavingevidence.wordpress.com/2017/04/12/access-intimacy-interdependence-and-disability-justice/> [accessed 1 December 2022]. Emphasis in original.

conversations and piece together the relationship and trust that we know we need for access'.[19] Access means that labour is shifted away from the disabled or ill person, and that it is therefore more equally distributed. These definitions from the chronically ill and disabled community share an emphasis on access as process, exchange, and interaction rather than a state that can be achieved.

The Covid-19 pandemic has accelerated the interest in access measures, particularly in digital spaces where auto-description has become more widespread and textual transcription more easily available. In the art world, expanding accessibility has become part of the movement to decolonise museums and galleries, thinking about how to make collections and exhibitions relevant to more diverse audiences. Curator and academic Amanda Cachia describes a nascent movement away from 'taped-on' access measures, added after the works are executed and aimed at making them comply with minimum access requirements, towards a more holistic understanding of access as 'praxis and not simply policy'.[20] This approach sees artists including 'access as an integral and critical part of their artwork' in which it is 'creative and experimental'.[21] Adding more sensory aspects, such as sound, smell, touch, and taste, is an example of how artworks and exhibitions can be accessible at more experiential levels in a way that likely improves the experience for all visitors.

Curators and artists can integrate access into every part of their collaborative work, considering it 'a theoretical and practical generative force'.[22] This may mean more flexible approaches to workflows and deadlines, as well as integrating so-

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[19] Mingus, 'Access Intimacy, Interdependence and Disability Justice'. Emphasis in original.

[20] Amanda Cachia, 'Introduction', in *Curating Access: Disability Art Activism and Creative Accommodation*, ed. by Amanda Cachia (London: Routledge, 2022), pp. 1–14 (p. 2).

[21] Cachia, p. 2.

[22] Cachia, p. 2.

called *access features* into the works. Examples of using the affordances of access features to enhance an artwork include the work of Bojana Coklyat and Shannon Finnegan's workshops on 'alt text as poetry'.[23] Coklyat and Finnegan utilise *alt text*, the text added to digital images to make them comprehensive to people using screen readers, as a creative medium and an additional dimension of an existing artwork. This effectively dissolves the distinction between access measure and artwork. Many contemporary illness writers, including Hedva and Lazard, provide captions for images included in their texts, audio recordings, and make sure their texts are printed using fonts more easily legible to people who are dyslexic. These are not only access measures but also ways to make a literary work transcend the printed page, with e.g., an audio recording adding new affective and experiential aspects to a work. Access measures can therefore be an important aspect of the aesthetic object.

While access labour can be undertaken by anyone, however, the responsibility very often ends up falling on those who are disabled. As Aimi Hamraie observes about the difficulty of accessing even feminist spaces: 'I am often asked to perform the labor of creating access for myself, whether by lending knowledge, sharing resources, or devising solutions'.[24] This labour is often invisible to those who are not marginalised if it is not described by those who are chronically ill and disabled.

In 'Why It's Taking So Long', Hedva describes how the amount of *access work* they needed to do sharply rose as a consequence of the success of 'Sick Woman Theory'. Following on from the previous chapters, what is the 'work' in 'access work'? The tasks Hedva describes having to undertake constitute labour

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[23] Bojana Coklyat and Shannon Finnegan, 'Alt Text as Poetry', 2021 <https://alt-text-as-poetry.net> [accessed 14 May 2023].

[24] Hamraie, p. 262.

which is time-consuming, require considerable effort and energy, and is unpaid. Invoking the concept of 'work' in relation to these tasks makes visible the extent and value of their labour. The tasks are displaced, insofar as organisations would normally be expected to hold the responsibility for accessibility. However, most of the organisations have only made a cursory effort; maybe they have ensured accessibility for people in wheelchairs, but not the more complex negotiation of access requirements for people with chronic illness. This once again demonstrates that chronic illness entails significant and skilled activity, but also documents the failures of organisations to meet their responsibilities.

Several critics describe how the difficulty of undertaking access work can sometimes make it seem almost redundant. As Desiree Valentine writes:

> what can be "gained" from access needs being met is offset by the *labor* of access work itself, which can compound the need for accommodation in the first place. Even in situations where access is accounted for and accommodations are made, what falls out of the picture is just how strenuous or deflating on a *relational* level this access achievement might have been.[25]

Access work has emotional and relational consequences that means it is not always worth the trouble. This is also emphasised by Annika M. Konrad, who uses the term 'access fatigue' for 'the everyday pattern of constantly needing to help others participate in access, a demand so taxing and relentless that, at times, it makes access simply not worth the effort'.[26] Konrad describes this effort as a form of communicative labour required from people who are disabled, who must take pains to come across in just the right way if they are to continue being liked and respected by others. Access work often involves the labour of a network of people, as indicated by the involvement of curators, organisational staff, publishers, and editors. This

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[25] Valentine. Emphasis in original.

[26] Annika M. Konrad, 'Access Fatigue: The Rhetorical Work of Disability', *College English: Urbana*, 83.3 (2021), 179–99 (p. 180).

distinguishes it from the other types of illness labour analysed in this thesis. Milbern's and Mingus' descriptions of access cited above stress that it is an ongoing negotiation at least and a community-building empathetic exchange at best.

The demands of access work—this is the answer to the question posed in Hedva's essay title, 'Why It's Taking So Long'. In their own description, it is taking Hedva so long to produce new artworks because of the demands of becoming a public disability and illness advocate and the access work they need to undertake for themself to continue their creative work and build a career. Hedva's descriptions of needing to undertake this informational labour to be able to accept the invitations extended to them, as well as to make ways for others, demonstrate that although works about chronic illness and disability are increasingly seen in the mainstream, ill and disabled artists and writers are still only offered marginal spaces. In Hedva's account, they are paid low fees, there is little budget for expenses, and they are expected to be grateful for the exposure. While illness writing has become a more defined 'product' with a larger audience, there is therefore still a long way to go in the activist struggle for the accommodation of chronically ill people in social spaces, culture, and workplaces. However, the text marks a significant development within contemporary feminist illness writing: a moment when authors start reflecting on their own change in status, and the change in status of the genre of illness writing more broadly.

The essay also points toward a new stated intention of the literary illness text. Whereas 'Hedva's Sick Woman Theory' makes a claim to activism based on the representation of a marginalised population, 'Why It's Taking So Long' describes a more practice-based activist approach focused on improving the accessibility of workplaces like arts organisations and the literary world. The access work, Hedva writes, 'is the only part of my public role as the Sick Woman that feels like it is worth anything'.[27] Doing access work, Hedva writes,

> takes this condition of "being seen as" by something external and returns a small amount of agency to me in terms of what I can do with it. It's not some chip I can cash in for my ego, but something that might make meaningful change and bring actual support to the disabled community. It is not performative—and it is often the only thing that feels that way. Institutions love to perform themselves, their "ethics," their "values," and the main way they do this is by shoving their fists up the asses of puppets like me.[28]

Access work is a way of seizing the little power that the artist has achieved and put it to use. If institutions need chronically ill artists for their funding applications and to gain legitimacy, artists like Hedva can aspire to leave some marks on the institutions in turn.

Access documents and institutional critique

In this thesis, I am interested in how we can be sensitive to illness writing as a both literary and activist 'practice', and how the interplay between the two shapes contemporary feminist illness writing. We tend to see the effectiveness of activist texts as deriving from clear objectives and measurable impact, whereas 'literariness' rather derives from the ways in which texts destabilise and complicate meanings.[29] Making an argument about their activist purposes may miss the 'literary' aspects which often complicate and problematise the issues they are interested in. On the other hand, focusing on literary style can mean failing to pay attention to the interventions made by the texts. In this chapter, I argue that the activist aim of the texts is to model and perform access work. I propose that the concept of *institutional critique* in turn illuminates how the access work in these texts is entangled with

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[27] Hedva, 'Why It's Taking So Long'.
[28] Hedva, 'Why It's Taking So Long'.
[29] Levine, *Forms: Whole, Rhythm, Hierarchy, Network.*

literary experiments with genre, challenges to norms in the workplace, and engagement with the visual arts. I start with a reading of a text that sits on the intersection of work document, activist practice, and literary illness text.

As a response to institutions without comprehensive accessibility, Hedva describes starting to formulate a ‘Disability Access Rider’, first conceived of as a document they could send to organisations and institutions who extended invitations to them. Hedva recounts starting to write the ‘rider’ around ‘six months into the Sick Woman storm’:[30]

> I started making a list of accessibility requirements that I would need if I were going to work with institutions, so they could host my disabled ass and make the event accessible for the audience. The document began as a necessity—I had to put into emails that, if I were to stay overnight for the event, I’d need to sleep in my own bed in an actual room, and not on an air mattress in an unheated hallway, because bitches tried it. I had to write that the venue hosting the disability conference had to be wheelchair accessible because bitches, so many, tried it.[31]

After using it for personal needs and sharing it with friends, Hedva published the document on their ‘sick woman’ Tumblr blog in 2019, and it has since been included in the accessibility resources on the website *Access Docs for Artists* and published in the edited volume *Curating Accessibility* (2022). Hedva describes it as ‘an itemized list of all the things I’m going to have to pour uncompensated educational labor into’.[32] The rider makes the labour Hedva needs to undertake to keep a speaking commitment clear and attempts to hold the receiving institution to a similar commitment and responsibility. It is heavily hedged:

> Before I can commit to that process with you—and honey, it is a pro*cess*!—please take a moment to read the below, and let me know *how* you can support *each* item. If you need more specifics about any component, ask me. I’m happy to clarify and assist where I can. If you can’t provide something on this list, let’s have a

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[30] Hedva, ‘Why It’s Taking So Long’.
[31] Hedva, ‘Why It’s Taking So Long’.
[32] Hedva, ‘Why It’s Taking So Long’.

> conversation about it. I am more interested in accessibility as something for which we work together, rather than a punitive standard I measure you against.[33]

The use of ‘honey’ as an ironic term of endearment is juxtaposed with the ask of requiring up-front labour from the institution in terms of reading and responding to each item on the list. The colloquialism pushes back against a conventional ‘professional’ style, instead positioning the exchange as collaborative and potentially affectionate, even if the mention of a ‘punitive standard’ suggests that the tone of the relationship can easily change.

The idea of a ‘rider’ plays on the stereotype of a diva or a rock star with unreasonable and excessive demands. It anticipates a response of being seen as ‘difficult’ and addresses this directly through its form and title. The rider is detailed but also humorous, striking a tone between requirements and suggestions. Hedva writes:

> I cannot participate in anything before 16:00. I, and my audience, cannot sit for longer than 90 minutes without a 15-minute break. I require a dressing room/backstage area, and would not be bothered if fresh flowers appeared there. On the stage, I require a cushioned chair with a back for the entire event; I cannot stand.[34]

Hedva charts out a sense of a distinct audience, with distinct access needs that shape the form of the event. Some needs, like requiring a cushioned chair on stage, are straightforward. Others, like the comment that they would ‘not be bothered if fresh flowers appeared’ in the backstage area, get closer to the image of the demanding rockstar. The verb ‘appeared’ effaces the labour of the person who will need to arrange for that to happen. Although accessibility is often seen as being related to minimum requirements and the acts of removing barriers to entry, Hedva pushes

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[33] Johanna Hedva, ‘Hedva’s Disability Access Rider’, *Sick Woman Theory*, 2019 <https://sickwomantheory.tumblr.com/post/187188672521/hedvas-disability-access-rider> [accessed 1 December 2022]. Emphasis in original.

[34] Hedva, ‘Hedva’s Disability Access Rider’.

these boundaries, suggesting that objectives are not for ill and disabled writers to be tolerated, but for them to be valued for their distinct contributions, receiving the more luxurious features offered to established artists.

The accessibility rider is a working document, as indicated by the sign-off:

> I welcome anyone who wants to use this as a template for your own rider, or to share with institutions who invite you to do stuff. And I invite anyone working within the institution to use it too. Please copy/paste and circulate![35]

However, the contexts in which it is placed by Hedva indicate that it crosses generic boundaries. The fact that it is published on a website of resources, in a scholarly volume, as well as included in the writing project 'This Earth, Our Hospital' on Hedva's website with equal status to 'Sick Woman Theory', 'Why Its Taking So Long', and their other writings about illness, shows that it should not be excluded from analysis of Hedva's literary oeuvre. The act of publishing 'work documents' as literary works follows the tradition of *institutional critique*, a term most used in visual arts criticism. Since the 1960s, artists working within the broad category of institutional critique have criticised cultural institutions and the way they use their power. The feminist artists collective The Guerrilla Girls, for example, make artworks that double as campaigns pointing out gender and racial inequality in the art world. The term has a specific queer, crip, anti-racist, and feminist history, as seen in the work of some of the artists most associated with the term, AIDS activist and artist Felix Gonzalez-Torres, feminist artist Maria Eichhorn, and Native American artist Fred Wilson. As Grigely writes, institutional critique is a 'reflexive form of art, using the institution and its policies, protocols, and programs as media, and

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[35] Hedva, 'Hedva's Disability Access Rider'.

refiguring them as art'.[36] In classic works associated with the term, elements which are normally adjacent to an artistic practice, such as artists' contracts, wall labels, or curatorial tours have all become the artworks exhibited.[37]

Traditionally, access work is undertaken in the periphery of the art world and publishing. Negotiations take place between artists, agents, institutions, and audiences on accessibility. If the artist does not believe they are being treated fairly or accommodated to a reasonable degree, they can lodge a complaint or file a lawsuit. In attempting to achieve local changes in art institutions—and turning these efforts into artworks—Hedva and other contemporary feminist illness writers build on a tradition of institutional critique and illness activism pioneered by artists during the AIDS epidemic. In 1978, the American playwright Ron Whyte established the activist organisation *A.N.D.: The National Taskforce for Disability and the Arts*. The acronym stood for 'Arts Need the Disabled,' which, as Grigely observes, 'inverts the usual therapeutic approach about how art is "good" for people with disabilities'.[38] The projects undertaken by the organisation included lawsuits against theatres with no wheelchair access. This approach suggests that just as access features can make an artwork richer, the lens of chronic illness and disability politics can improve arts institutions for everyone.

Institutional critique describes the way the boundaries between artwork and activism are blurred in ways that expose and imbricate institutions. Like the A.N.D., Hedva hopes that the implementation of their own access needs can lead to better and more accessible art spaces for all. As Hedva writes in the 'Disability Access Rider',

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[36] Joseph Grigely, 'Foreword', in *Curating Access: Disability Art Activism and Creative Accommodation*, ed. by Amanda Cachia (London: Routledge, 2022), pp. xix–xxii (p. xx).

[37] Grigely, pp. xxi–xxii.

[38] Grigely, p. xx.

> It would be so cool, and you'd make me and my friends and many others very happy, and you'd increase the attendance of your events by a lot, and you'd become a working part of building the kind of world that needs to be built, if you would follow this document not just for me, but for all your work in the future.[39]

Hedva presents institutional prestige, happiness, increased attendance, and being part of building a better future as rewards for participating in the process. The intention is to change work practices, hopefully in ways that have longer-term implications, even if Hedva describes knowing that often, 'the moment I wasn't there to make my demands, everything went back to how it had been before'.[40] While Hedva remains ambivalent about the actual impacts of 'disability riders'—something also underscored by the fact that the e-mail cited in the introduction is a documentation of the failure of the riders created by the participants of the residency—sending it remains an attempt at building this possible future.

The 'disability rider' is not the only example of this approach. The accessibility guide, something that almost all arts institutions have, is perhaps the most utilitarian access document type. It provides practical instructions on, for example, how to implement sign language interpretation and how to cater for a neurodiverse audience. Examples are those created by Arts Council England or the Smithsonian Institute in the US.[41] These are typically seen as non-artistic work documents. However, the accessibility guide has also been used by artists as part of their practice. Lazard's 'Accessibility for the Arts: A Promise and a Practice' (2019)

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[39] Hedva, 'Hedva's Disability Access Rider'.

[40] Hedva, 'Why It's Taking So Long'.

[41] Jayne Earnscliffe and Arts Council Capital, 'Building Access: A Good Practice Guide for Arts and Cultural Organisations' (Arts Council England) <https://www.artscouncil.org.uk/sites/default/files/download-file/Building_access_guide_260319_0.pdf> [accessed 4 January 2023]; Janice Majewski, 'Smithsonian Guidelines for Accessible Exhibition Design' (Smithsonian Institution Accessibility Program) <https://www.thc.texas.gov/public/upload/publications/Smithsonian%20Guidelines%20for%20accessible%20design.pdf> [accessed 4 January 2023].

is a guide commissioned by the organisation Recess and hosted on a website in the form of both a pdf and an audiobook, both free to download. It has four parts, 'Why Accessibility?', 'Accommodations', 'How to List Access Information', and 'Budgeting' as well as an acknowledgments section, and is described as 'an accessibility guide geared toward small-scale arts nonprofits'.[42] Lazard links it prominently on their website as a category of their practice alongside 'Videos' and 'Work Images', and the project 'The World is Unknown', also suggesting a continuity with the rest of their artistic oeuvre.[43]

In the first section of the guide, Lazard places it within the movement of *disability justice*, 'the second wave of the disability right movement, transforming it from a single issue approach to an intersectional, multisystemic way of looking at the world'.[44] Citing a statistic that a fifth of Americans are disabled, Lazard posits accessibility measures as a 'surefire way' for smaller arts organisations to expand their audience.[45] Although the language is generally business-like and unadorned, intensifiers like 'surefire' add a colloquial and personal tone to the first-person narration of the piece. Even if it is described as a 'guide' to future action, Lazard uses the document to comment on the injustices of the art world in its current form, observing, for example, that 'there is often a striking discord between an institution's desire to represent marginalized communities and a total disinvestment from the actual survival of those communities'.[46] The guide moves from practical instructions of how to address someone who primarily communicates through lipreading to more abstract statements such as that 'To commit to disability justice is to redefine the

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[42] Carolyn Lazard, 'Accessibility in the Arts: A Promise and a Practice', *Promise and Practice*, 2019, p. 6 <https://promiseandpractice.art/>.
[43] Sidebar, www.carolynlazard.com [accessed 10 January 2023].
[44] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 6.
[45] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 7.
[46] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 9.

terms of subjecthood'.[47] In the text, accessibility determines literary form: font, size, use of bold and capitals, use of bullet points. But Lazard also explicitly questions genre, likening the access document to utopian fiction by writing that 'accessibility is a promise, not a guarantee. It's a speculative practice'.[48] Lazard stresses that accessibility requires 'great flexibility' and 'demands a malleable infrastructure that shifts, in real time, with the needs of the community'.[49] The local negotiation of practices surrounding the exhibition of artworks or publication of a text thus come to stand in for a network of global exchange.

Other illness writers likewise insist that their 'access' texts are part of their literary oeuvre. In *Care Work: Dreaming Disability Justice* (2018), a collection of texts published over a longer period, Leah Lakshmi Piepzna-Samarasinha juxtaposes essays focusing on access with more experimental literary writing. She uses the following justification:

> Like disability justice itself as a framework and culture, this book is a mix of very concrete tools and personal essays. I hesitated a bit to include the former. Serious cultural work isn't supposed to include lists of fragrance-free curly hair products or instructions about how to tour while sick and hurt less, right? But—*fuck that.* The making of disability justice lives in the realm of thinking and talking and knowledge making, in art and sky. But it also lives in how to rent an accessible porta potty for an accessible-except-the-bathroom event space […]. And neither is possible without the other.[50]

Piepzna-Samarasinha argues that form follows purpose, and that mixing genres is integral to the type of writing she is doing, also grounded in disability justice. She combines conversational language ('right?'), linguistic creativity and neologisms ('an accessible-except-the-bathroom event space'), with swear words and expletives.

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[47] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 9.
[48] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 10.
[49] Lazard, 'Accessibility in the Arts: A Promise and a Practice', p. 10.
[50] Piepzna-Samarasinha, *Care Work*, pp. 23–24.

The more colloquial language is combined with academic concepts, poetic phrases ('in art and sky'), and metaphor, making for a style that can encompass academic discussions but also take considerable creative licence. Like Hedva's 'Disability Access Rider' and Lazard's 'Accessibility for the Arts: A Promise and a Practice', Piepzna-Samarasinha's work combines practical and more abstract objectives. Both the accessibility guide and the disability or illness rider are types of text that are in the process of being established as genres in their own rights. Together, the texts show different ways in which contemporary feminist illness writers use access documents as a genre in their works, exemplifying how the labour done by chronically ill writers shapes the forms of their texts.

In these texts, the activist and the literary objectives collide. These texts are not just working documents, but are used in transactions between artists and institutions, and intervene, at least for a while, in local practices. I argue that these texts should be seen as part of contemporary feminist illness writing, working in collaboration with the more traditional literary texts. Reading these texts as forms of institutional critique, using the processes and bureaucratic forms that traditionally only support artworks as artworks in themselves, is a way of conceiving of the relationship between literary and activist objectives as intertwined. Creative work necessitates access work which in turn *becomes* artwork. But it is not that the act of elevating the access work into artwork makes it more valuable. Rather, the concept of institutional critique underscores that all acts of access work are work and should be recognised as such. Including access work in artworks is a way of drawing attention to and re-valuing the invisible labour being undertaken by many of those who are chronically ill or disabled but not artists.

Moreover, applying this concept from art criticism to literature is apt in the context of contemporary feminist illness writers, demonstrating the influences from visual art practices and art history on the texts. Hedva, Lazard, and Piepzna-Samarasinha are all educated to MFA level at art schools and work across multiple artistic mediums including sculpture, installation, and performance. Although I refer to them primarily as 'writers', their backgrounds and creative practice in visual arts shape their literary work, and by virtue of their influence, contemporary illness writing more generally. This, I argue, makes it important to discuss the texts with reference to how they engage with art historical traditions and concepts. The importance of the sector for illness writing is also shown in the presence of art institutions in the texts cited above. Hedva's 'Why It's Taking So Long' is primarily a critique of art institutions. This reflects that while many of the texts have been received well in the literary community, it is arts institutions which have really seized on illness, disability, and care as important themes in recent years. The next section will elaborate the collision of access work and creative work in forms associated with bureaucracy, looking particularly at Hedva's use of the e-mail in their essay.

Bureaucracy, normalcy, and the e-mail

As opposed to my reading of access work as equally important to artistic work, Hedva initially sets up a clear hierarchy between the two in 'Why It's Taking So Long'. Hedva contrasts their 'actual work', i.e., their creative practice, with the need to do access work. Hedva describes crying when an audience member at an event asks: 'If you didn't have to do all this work about access, all this labor, send all these emails, get into all these fights, what would you do? Like, if you were just—

welcomed. Supported. What would you make? What is your *actual* work?'[51] The e-mails are included in the essay as documentation of acts of access work, but the intrusion of this 'work genre' into the essay also mirrors the way access work has replaced 'artistic' work for Hedva. In the essay, Hedva describes access work as having used up their limited energy, stating: 'I wish I'd written things other than angry emails in 2021, but if this is all I got, I might as well try to make it useful. Use what you have, they say'.[52] This recalls the mode of artistic traditions such as *arte povera* and collage which reuse materials, and in particular the Black American artistic tradition of using pre-created and found materials as an homage to the necessity of re-using and re-casting among populations who have been deprived of resources. Rather than using found materials, however, a poetics of impairment means finding ways to re-use labour. Like the authors including notes and diary extracts in their texts as analysed in Chapter 1, inserting e-mails into the essay allows Hedva to turn what has distracted them from their writing into part of their literary output. This allows them to reclaim these efforts as acts of skilled and creative work which can be remunerated. The essay thus dissolves the boundaries between access work and literary work, claiming the two as continuous. Hedva elevates the e-mails from supporting documents, created simply to facilitate artistic production, to pieces of writing that sit at the centre of an artistic practice and ethos informed by anti-ableism.

The e-mails are documentations of work but also *about* work. They consider and challenge the distribution, quality, and fairness of work in the art world. In the e-mail cited in the introduction to this chapter, the labour of the residents, the

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[51] Hedva, 'Why It's Taking So Long'.
[52] Hedva, 'Why It's Taking So Long'.

overworked staff, and the unpaid labour Hedva undertakes in sending the e-mail are all foregrounded. In another e-mail, Hedva describes curators ‘weaponizing information about the labor behind the show’.[53] They tell the curators: ‘you’ve extracted an enormous amount of educational labor from me behind the scenes, all while exploiting my work, name, and cultural capital to a public who has no idea what’s gone on under your roof’.[54] The concepts of weaponisation, extraction, and exploitation position the arts institution as predatory, capitalistic, and even violent; even if Hedva also gets back at the institution by ‘weaponizing information about the labor behind the show’ in making the e-mails public.

The concept of ‘labour’, and the many ways in which it is used in the essay, has the effect of conflating very different tasks, responsibilities, and actions. The labour behind the show includes creative work but also, presumably, administrative and logistical work, which are different from the ‘educational labor’ to inform the institution about accessibility practices. Artistic work, the negotiation of personal accommodations, and the activist labour of improving accessibility become hard to distinguish from each other. These different types of labour also come together in an assertion in the same email, where Hedva writes:

> care is not a virtue signal. accessibility is not performative. my disability cannot be mined as an abstract concept. my body cannot be separated from my work.[55]

Hedva insists on the material realities of care, accessibility, and disability in the context of the art institution in which these are often reduced to intellectual concepts or themes. But the final use of the concept of ‘work’ also completes the effect of conflating different kinds of labour. It is ambiguous whether it refers to creative or

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[53] Hedva, ‘Why It’s Taking So Long’.
[54] Hedva, ‘Why It’s Taking So Long’.
[55] Hedva, ‘Why It’s Taking So Long’.

access work, possibly as a way of underlining that it does not matter: it is all work, which means it takes precious time and energy but also that it may bring about changes.

In addition to documenting work, and being about work, the e-mail is a textual genre and a communications medium closely associated with work. Specifically, it is associated with office work and other immaterial labour. Together with pointless meetings, e-mails are often used as an example of how workers waste time, such as by David Graeber who cites it as one of the primary components of 'bullshit jobs'.[56] Similarly to the styles employed by Piepzna-Samarasinha and Lazard, Hedva blends poetical formulations with more prosaic requests referring to fees, specific deadlines, and information flows. Hedva's emails have a distinct style. They preserve some conventions of the genre, having a subject line, time stamp, address, and sign-off. However, writing in all-lowercase letters is a way of challenging other conventions, making sure the e-mails stand out.

As a communications media in which much work information is exchanged, e-mail also has a particular relationship to contemporary bureaucracy. Titchkovsky describes the connection between access work and the bureaucratic, positing bureaucracy as a privileged site on which to observe the negotiation of *normalcy*. The paradox of bureaucracy, Titchkovsky describes, is that it is 'conceived of as protection against personal arbitrariness while also inhibiting an organisation's capacity to be responsive to the essentially irregular character that is human life'.[57] This can be recognised in the depictions of access work by Hedva and Piepzna-Samaransinha, who describe disability advocacy as constantly coming up against

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[56] David Graeber, *Bullshit Jobs: A Theory* (London: Allen Lane, 2018), p. 46.
[57] Titchkosky, p. 9.

institutional expectations and definitions of what is ‘reasonable’. The legal formulation of ‘reasonable adjustments' (UK) and ‘reasonable accommodations’ (US) in reference to disability are constructed with reference to social norms. What is ‘reasonable’ is subject to change over time. This underlines the importance of sometimes pushing the boundaries and being seen as ‘unreasonable,’ for example when sending a rider or asking for fresh flowers backstage. Challenging the norms surrounding what someone can ask for is necessary for the norms to change over time.

While institutions may now expect their audience to be more diverse, there is still an expectation that the artists are abled-bodied, which Hedva’s e-mails challenge. Titchkovsky describes bureaucracy as ‘a prevalent productive force constituting conceptions of regular procedures, normal participants, and typical processes as these are formed over and against the abnormal, the troublesome, or the exceptional’.[58] Moreover, she points to the ways in which institutional structures ‘produc[e] forms of subjectivity, such as the good worker, student, or recipient of services, or the citizen and the immigrant’.[59] The e-mails are evidence of Hedva using the existing system of negotiation associated with bureaucracy and business, but tweaking it stylistically to fit themself and their needs. The all-lowercase writing, large poetical and ethical statements, and emotional use of language all interrupt the ‘professional’ expectations of the bureaucratic e-mails and the scaffolding work of navigating institutional procedures.

The ways in which Hedva’s style challenges the professional expectations of the e-mail form has a parallel in how the inserted, full-length e-mails challenge the

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[58] Titchkosky, p. 9.
[59] Titchkosky, p. 9.

literary form of the critical essay. The language varies wildly, from confessional to financial, political to prosaic, lyrical to factual, dissolving boundaries between the figure of the 'artist', allowed to be emotional, and the 'worker'. By elevating the emails to literary text, Hedva comments on necessity of doing less. Including the e-mails is a labour-saving tactic which assists the ill writer, but which also presses at the boundaries of the sanctioned forms of subjectivity as Titchkovsky describes. Like Lazard's access guide, which makes a proposed intervention into institutional practices by offering itself up as a new set of guidelines which organisations can adopt, Hedva's e-mails comment on their own role in bureaucracy. E-mail is a medium which is inherently about the archival and re-production. Each message repeats the previous ones in the correspondence, and is easily forwardable, making it a genre that is useful for holding someone accountable. Once an e-mail is sent, it is archived in digital repositories in such a way that it is very difficult to delete or hide. Hedva exploits these functions. The redaction of the e-mails emphasises that the critique is levelled at the sector as a whole. But the identifying characteristics preserved in the e-mails also mean that the essay serves to shame individuals and organisations. The inclusion of dates, details, and references to Hedva's social media profiles make it easy to find the original recipients. The e-mails function as proof and documentation, but also work on the interface of public and private documents; as official correspondence, they can be published, even if the original context did not indicate that this would be done.

E-mail has become a common form included in literary texts, particularly in contemporary fiction. In novels by e.g., Sally Rooney and Elif Batuman, central relationships are charted by and developed through e-mails sent between the main characters.[60] Memoirs can also include e-mails and epistolary works of e.g., criticism are written as e-mail exchanges.[61] But Hedva's text is not an exchange—it is only one side of a conversation. There are no respondent e-mails reproduced in the essay. This absence plays up the contrasting amounts of labour that they call out in the e-mails themselves. They formally reproduce what Hedva claims is true for the processes: that the effort is all done by Hedva, with very little received in return. In addition to their literary properties, the e-mails also contain the most 'practical' aspects of the essay, as examples of activist practice which others may learn from and even copy and paste when they need to. Hedva writes that they hope the e-mails can be 'lodestars for people who need to write emails of their own, to give courage to those who want to write the email but don't'.[62] As such, they undertake a didactic function, teaching others how to advocate for better accessibility.

'Why It's Taking So Long' places the modes of production into the very centre of the text and is transparent about the process of publication. It makes visible the 'work' behind a finished literary work by setting up an almost forensic timeline:

> I began writing on December 18th, 2014, in a flare, lying in bed. Over the next year, the essay was rejected by over a dozen publications and some of the biggest names in feminism before finding a home in *Mask Magazine*, which was ad-free, online, and run by a volunteer group of anti-capitalists in their twenties. I was paid $81, the highest amount that *Mask* paid its writers. Because there were no ads, no one made any money.[63]

Like the lists of treatments and strategies described in Chapter 3, details about payment received for the publication of texts and how the author has navigated speaking events and access are a common feature of literary illness texts. Khakpour,

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[60] Sally Rooney, *Beautiful World, Where Are You* (New York: Farrar, Straus and Giroux, 2021); Elif Batuman, *The Idiot* (New York: Penguin Books, 2018).
[61] See e.g., Joan Didion, *The Year of Magical Thinking* (New York: Knopf Doubleday Publishing Group, 2007); Sarah Chihaya and others, *The Ferrante Letters: An Experiment in Collective Criticism* (New York: Columbia University Press, 2020).
[62] Hedva, 'Why It's Taking So Long'.
[63] Hedva, 'Why It's Taking So Long'.

for example, also describes the multiple editors and publicists who worked on, and then left, the project of publishing *Sick*. The writers thus emphasise that the text is an object which is shaped by its network of production and a number of actors beyond the author. Hedva is honest about the low pay and many rejections they have experienced, going into extreme detail on their financial situation:

> I had medical costs that eclipsed my annual income several times over; the year that "Sick Woman Theory" was published I was on food stamps. My gross income on my 2014 tax return, my last year of grad school, was $5,730. In 2015, it was $7,173. In 2016, it was $9,255. I was a part-time freelancer whose disability kept them from working full-time, but I was ineligible for disability benefits because my conditions—endometriosis, fibromyalgia, chronic PTSD—were seen as not debilitating enough, not that bad.

This type of disclosure creates a sense of full transparency into the difficult circumstances of being a graduate student and early career artist while also ill. These circumstances are placed as central to the text, its form, and the marginalised position from which it was written and published.

Hedva does not disclose their financial details after 2016, which is when they started to achieve success. Hedva describes saying no to a lucrative deal for an illness memoir, and to other similar opportunities which they felt would not suit their artistic ambitions. However, in the period between 'Sick Woman Theory' and the writing of 'Why It's Taking So Long', Hedva published two books (a third forthcoming in 2023) and exhibited at institutions including Gropius Bau in Berlin, Rønnebæksholm in Denmark, the Wellcome Collection, Parrhesiades, and Modern Art Oxford in the UK. Hedva does not mention these events in the essay, or provide financial data for this period, which is their right. It is, however, worth considering the incongruity of a narrative of success with feminist illness writing as it has so far existed, as is apparent in the emphasis in 'Why Its Taking So Long' on precarity rather than the relative amounts of power achieved over the same period.

Contemporary feminist illness writers benefit from better funding, access to bigger publishing and arts venues, even if they also document the frequent hollowness of being invited into the mainstream. Mia Mingus' essay on 'access intimacy' was first published on her blog in 2011, while the second version from 2017 is a transcript of a lecture given at a conference. Piepzna-Samarasinha's texts come from grassroots organising starting in the 1980s, but while earlier texts such as 'Fragrance Free Femme of Color Genius' were published on her blog, *Brownstargirl*, later texts like 'A Modest Proposal for a Fair Trade Emotional Labour Economy' (2017) was published by *Bitch Media*. The collection *Care Work* (2018), in which both texts are included in new versions, was published by the small Canadian publisher Arsenal Pulp Press but was a commercial success and is available in mainstream booksellers. Lazard's accessibility guide is published just after they started to gain popular success; they are now an internationally successful artist, whose works are collected by institutions including MoMA in New York. If contemporary feminist illness writing as a grouping, and individual writers like Hedva, continue their assimilation into the mainstream, a new, more powerful positionality will have to be reckoned with. The theorisation of improving accessibility is the first step towards this, but the process will likely have other additional aspects which impact on the forms of the texts.

A literary ethics of access

The texts about access primarily respond to museums and other art institutions, rather than literary institutions such as magazines and publishers. This may point to the fact that literary publishers, especially small presses and magazines, have been quicker to incorporate access for artists who are chronically ill into their ethos. Many of the magazines founded to publish contemporary feminist illness writing in recent years take an approach which prioritises the creation of an accessible workplace culture equally to the quality of the artworks they publish. These magazines are run by and for precarious and/or ill writers, such as the now defunct *Mask Magazine* in which 'Sick Woman Theory' was published. In the 'Editor's Letter' to the first issue of *SICK Magazine*, Olivia Spring emphasises that workplace practices are as important as editorial choices in creating an accessible outlet:

> I wanted to work, but in an environment where I didn't feel guilty or got yelled at for needing a day off. I dreamt of others who felt the same joining me, all of us being unreliable and sick and supportive together. I wanted, so badly, to be the employer that offered all the things I desperately needed.[64]

In an interview, Spring describes the measures she implemented as including flexible deadlines and a longer timeframe for editing and producing the magazine.[65]

However, Hedva calls out large mainstream publishers in the body of 'Why It's Taking So Long' for only wanting to publish an illness memoir in the style of 'Sick Woman Theory' rather than texts by Hedva on other subjects. They write:

> When [a book contract] was offered to me, I saw only the strings attached, the price. I saw that they would want an illness memoir and not what I wanted to write, which was an analysis of ableism fractured through different literary forms that refused to be contained in a traditional genre. I saw that they'd want me to write a book with more answers than questions, which was the opposite of what I had. I saw that they'd want me to lead the parade of chronic illness to the peak of its trending topic, which, at that time, was just starting its ascent in the mainstream. I saw that they saw only my hit, my one piece that went viral, not my body of work, nor the range of subjects I was inquisitive about, nor the genre-fuckery I felt the most allegiance to, nor the long and varied career I was aiming for. In short, they saw the Sick Woman—not me.[66]

This account of the publishers wanting Hedva to 'lead the parade of chronic illness to the peak of its trending topic' reflects how much and how rapidly the status of the

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[64] Olivia Spring, 'Editor's Letter', *SICK Magazine*, August 2019, p. 5.

[65] 'A Frank Conversation About Chronic Illness and Creativity', *Eye on Design*, 2022 <https://eyeondesign.aiga.org/a-frank-conversation-about-chronic-illness-and-creativity/> [accessed 1 December 2022].

[66] Hedva, 'Why It's Taking So Long'.

genre had changed. But while proven as profitable, Hedva's opinion is that the genre is not expansive enough generically or concerned enough with anti-ableist activist practices. 'Why It's Taking So Long' can thus be seen as an essay which tries to rectify this and model a type of activism that lives up to these objectives.

We can see the essay as an attempt at the 'analysis of ableism fractured through different literary forms that refused to be contained in a traditional genre'. The idea of anti-ableism as a textual practice and ethics, however, also relates to the theme of work in more complex ways. In 'Why It's Taking So Long', Hedva emphasises that an e-mail asking for accessibility-related accommodations triggers additional work processes for the staff and leadership of the receiving organisation. The complication is that in practice, accessibility requirements often create more work for individuals, typically a handful of conscientious staff members. Hedva recounts one member of staff telling them that it felt like Hedva 'was dumping all this extra work on her.' In the essay, Hedva replies that is the point:

> I nodded. "That's exactly what this document is about," I said. My Disability Access Rider is not a list of things we can "achieve" together if we just put our minds to it. If only! I'm not asking the staff of an institution to be more overworked, stressed out, and underpaid in working against ableism. I'm trying to point out that they already are—overworked, stressed out, and underpaid, that is—and it's *because of* ableism.[67]

Hedva acknowledges that the people who take on these tasks are often women, people of colour, and/or other disabled or ill people, who will 'personally try to make it work, putting in extra hours of their own unpaid labor'.[68] Creating more work for individual, already overworked staff members at arts institutions may be an imperfect first step, but Hedva sees it as key for a structural shift away from

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[67] Hedva, 'Why It's Taking So Long'.

[68] Hedva, 'Why It's Taking So Long'.

assuming able-bodiedness, towards a model that takes into account a diversity of abilities and capacities. Access work thus includes many different types of work, all of which aim to extend chronically ill or disabled people's opportunities by eroding assumptions of able-bodiedness one locality at a time, enacting disability theory in practice by intervening into workplaces.

This tension has a parallel in the tradition of artworks on the topic of accessibility. As Grigely observes, 'some of the most meaningful installations related to access issues have worked not by creating access to artworks, but by denying it'.[69] In the exhibition 'Ramps' (2014) at the Essex Street Gallery in New York City, the artist and writer Park McArthur asked local businesses and arts venues if she could borrow their ramps for the duration of the exhibition. More than a dozen places agreed, installing a sign in place of their ramp saying, 'Ramp Access Located at Essex Street'. At the end of the exhibition, no business asked for the return of their ramp, meaning that the exhibition in fact decreased access in the area. Andrew Blackley writes of McArthur's exhibition 'Ramps' that it 'enlisted generative, generous responses to the negativity of the institution, to the point of engendering the reproduction of those very negative characteristics (by removing the objects' previously assumed "function")'.[70] Taking an opposite but complementary approach, the blind American artist Stephen Lapthisophon staged the exhibition *With Reasonable Accommodation* (2001) at the Gallery 400 in Chicago such that it was almost impossible to navigate. Sections were cordoned off, prints were illegible and blurry, and artworks gave the sense of being broken. Grigely points to this as a prescient way of 'cripp[ing] the gallery experience', making access both a subject

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[69] Grigely, p. xix.

[70] Andrew Blackley, 'Park McArthur: Geometry, Material, Scale', *Afterall*, Autumn/Winter 2015 <https://www.afterall.org/article/park-mcarthur_geometry_material_scale> [accessed 1 December 2022].

and a methodology.[71] The exhibition made able-bodied visitors have an experience more like that commonly had by blind or otherwise disabled visitors.

In ‘Why It’s Taking So Long’, Hedva creates a parallel to these two different art practices. The point is not to eradicate or reduce work, but rather to engender it; they put the institution they are working with under pressure, making the reliance on the overwork of individuals even more apparent. Hedva describes their aim as to redefine the body as ‘insolvent’:

> My Access Rider is not about sharing the load so that we can suddenly be in the black: it’s about redefining what being in the red means, what being insolvent to each other does, and it’s about acknowledging that we will *always* be there, covered, totally, in red.[72]

In a similar way to how artists working with access often foreclose access, Hedva describes making the burden of work even greater, to make the issue more easily recognised. Hedva’s ‘Sick Woman Theory’ argues that work in its current construction should be eradicated. However, in ‘Why It’s Taking So Long’, Hedva argues that the objective is more work for everyone. The work engendered by access is a very different type of work to the profit-maximising exchanges of concepts like Graeber’s ‘bullshit jobs’, however, even if it consists of as many e-mails. The work of access is conceived as meaningful exchange, a constant, reciprocated ‘asking after one another and making sure folks had what they need’ in the words of Milbern.[73] Accessibility, they argue, is a praxis and a political movement that has the aim of decoupling ideas of normalcy and morality from capitalist interests based on the ability to work and create profit.

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[71] Grigely, p. xix.
[72] Hedva, ‘Why It’s Taking So Long’.
[73] Stacey Milbern, qtd. as epigraph to Piepzna-Samarasinha, *Care Work*.

For the purposes of this thesis, the objective of improving accessibility as described in the work of Hedva, Lazard, Mingus, Piepzna-Samarasinha and others is significant because it illustrates a new conception of why the texts matter and the intended effect they will have in the world. Access work names the desired process started by the texts, creating an alternative to a concept like Arthur Frank's *dyadic bodies* that conceptualises the effect of illness writing on readers and the wider society. Moreover, the ways the writers move towards these objectives are interesting from a formal point of view: by utilizing the 'work genre' of e-mail and accessibility document, re-using labour already undertaken, and modelling techniques of intervening into institutions, they play with the medias of bureaucratic processes and the ways they enforce ideas of normalcy. However, through documents like accessibility guides and access riders, writers like Hedva and Lazard also attempt to adjust and improve the existing processes using the forms through which they are enforced and reproduced. The starkest example of this may be Piepzna-Samarasinha and Stacey Milbern's 'auditing tool' for organisations, a document which utilises the most important framework of legally sanctioned regulation.[74]

In this chapter, I have argued that Hedva, Lazard, and Piepzna-Samarasinha use their texts to intervene into workplaces. Rather than trying to influence a general public or raise awareness of particular conditions, they utilise the existing legislation which ensures that workplaces must be accessible. This is legally enforceable and one of the more clear-cut protections for ill and disabled people. Although this legislation is made to support economic incentives such as higher employment,

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[74] Leah Lakshmi Piepzna-Samarasinha, 'Disability Justice: An Audit Tool'. <https://static1.squarespace.com/static/5ed94da22956b942e1d51e12/t/625877951e18163c703bd0f4/1649964964772/DJ+Audit+Tool.pdf>

which the writers do not agree with morally, they nonetheless have decided to work through the channels that are available to them. The use of e-mail and other textual media and genres related to the world of work underline the degree to which the experience of being ill and disabled is bound up with work culture. There is a tension in anti-ableist advocacy work between advocating for measures of worth and dignity that extend beyond the ability to work, and working to create inclusive and accessible workplaces that recognize the ongoing negotiation and unique needs of chronically ill individuals to ensure their participation.

Writing is not only changed by being done in a state of illness; being an ill writer or artist brings on its own kind of work. The process of writing or creating art can be shaped by the intrusions of symptoms (Chapter 1), the labour entailed by illness (Chapters 2 and 3), and reception in the networks of production. As Hedva describes, occupying a public role as an ill *writer* (that is, being paid, published, and exhibited) also entails additional labour undertaken within the institutions one works with. Although theoretical, artistic, and political work on 'accessibility' builds on decades of scholarship and activism, the particular texts I have analysed here are written in response to the recent formation and relative success of a more coherent 'field' of chronic illness and disability artworks and writing, particularly since 2015. Leah Lakshmi, Mia Mingus, and Carolyn Lazard all describe having to be activists to take part in the art world. Although the art world may seem keen to profit from association with a 'new' marginalised population, a significant amount of access work is often required for chronically ill and disabled artists to be properly accommodated, and to secure access for a disabled audience. It was the fact of suddenly being invited into larger arts organisations and exposed to their often-majority white, middle-class audiences, and work practices geared towards the typically abled-bodied artists they were used to platforming that necessitated thinking, writing, and practicing access work. The ill writer is no longer a fully precarious worker, but their new status brings as many challenges as it does opportunities.

I have argued that access work is not just a theme, but a concept writers use to encapsulate an ethics of illness and disability writing. Placing the texts in relation to the art historical concept of *institutional critique* describes the relationship between the literary and activist objectives as mutually sustaining. Institutional critique elevates the work undertaken to navigate the (exclusionary) processes which upholds institutions, and the attempts to change them, from scaffolding to artwork. This, I argue, is typical of the way contemporary feminist illness writers co-opt textual forms more often associated with work into a hybrid genre that thinks actively about the relation of illness to work. If we consider contemporary feminist illness writing as a continuation of institutional critique, this also counters the tendency in the medical humanities to look at how illness writing 'services' medicine, something that has been criticised by proponents of a critical medical humanities approach, showing instead how accessibility can improve arts institutions for everyone.[75] Moreover, these new textual forms which include forms like the e-mail, the rider, and the accessibility guide are examples of illness writing which veer far from the form of the illness memoir, emphasising how contemporary feminist illness writers are developing new, non-teleological forms which better fit their changed literary and activist objectives.

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[75] Keir Waddington and Martin Willis, 'Introduction: Rethinking Illness Narratives', *Journal of Literature and Science*, 6.1 (2013), iv–v.

The tension between the chronically ill person and ideals of work and productivity intersects with larger issues of economic thinking and value in society. In the next chapter, I will explore how illness writing has a history of challenging dominant economic discourses and advocating for alternative measures of worth and value. By examining how illness writing disrupts and reimagines economic thinking, we can gain a deeper understanding of the broader social and cultural forces that shape the experience of chronic illness, as well as the contribution of contemporary feminist illness writing to ways of thinking human value otherwise. Having traced contemporary feminist illness writers’ engagement with concepts of work from the symbolic (e.g., through metaphor) to the concrete and material (bureaucracy, acts of access labour), the final chapter combines these in exploring how the texts engage with post-work thinking.

Chapter 5: Dreaming from the sick bed: ill perspectives and post-work theory

In *The Future is Disabled* (2022), Piepzna-Samarasinha considers how ill and disabled people have typically been used figuratively in mainstream futuristic thinking:

> In the Bad Future of all kinds of dystopian imaginings, disabled people are either everywhere, with our pathetic, pain-filled, dysfunctional, broken bodyminds. We're the tragic autistic son in Children of Men who can't look up from his devices, the "disfigured" ugly babies produced by toxic waste and climate change. We're a cautionary tale told to children, warning them to fight climate change and fascism or just look what will happen. On the other hand, in so much utopian social justice–oriented science fiction, it's unquestioned that in the good utopian future, disabled people don't exist. Everyone eats organic, and disabled babies are eliminated before birth through genetic selection that no one ever calls eugenics. In the happy future, we're all dead. And isn't it better that way?
> Fuck that.[1]

Reduced to a metaphor for human fallibility or the consequences of environmental pollution, chronically ill and disabled people have been denied full humanity in these visions of the future. This, she argues, not only perpetuates negative public conceptions of disabled people, but makes it harder for those who are disabled to imagine their own futures, 'disabled adulthood or elderhood'.[2] However, noting the collective work done within ill and disability communities to imagine societies in which the ill and disabled bodymind is centred, Piepzna-Samarasinha sets out to collect these 'crip futurities' in her text.[3] She does so by including a number of different forms and genres, including essays, interviews, conversations, recipes, and

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[1] Leah Lakshmi Piepzna-Samarasinha, *The Future Is Disabled: Prophecies, Love Notes and Mourning Songs* (Arsenal Pulp Press, 2022), p. 18.
[2] Piepzna-Samarasinha, *The Future Is Disabled*, p. 19.
[3] Piepzna-Samarasinha, *The Future Is Disabled*, p. 22.

access documents. Her intention is to provide a resource for the disabled community but also show the importance of this thinking that has been done on the margins. Knowledge from those who are ill or disabled may benefit everyone, not least when it comes to finding alternative concepts of value to those that have brought us to the current moment of inequality and climate crisis. As Piepzna-Samarasinha writes: 'the core of my work and life is the belief that disabled wisdom is the key to our survival and expansion. Crip genius is what will keep us all alive and bring us home to the just and survivable future we all need'.[4]

Piepzna-Samarasinha describes the act of imagining 'crip futurities' as 'the hard work of continuing to dream justice in the face of decades of brutality'.[5] The *hard work* of dreaming; once again, the register of work is invoked. On the surface, it is a paradox. But Piepzna-Samarasinha makes clear that she is not talking about leisurely daydreaming or the dreams which take place in REM sleep. The 'dreaming' she is concerned with is sustained, laborious, and done with open eyes: a collective effort which aims to change chronically ill and disabled people's conceptions of themselves and possibly the wider public's way of seeing disabled people, too. Piepzna-Samarasinha repeatedly juxtaposes the two concepts of work and dreaming, imagining disabled people supporting each other 'as they do the work of […] dreaming a new disabled life/world into being', something she describes as 'a very Black and brown disabled, collective way of doing the work'.[6] This formulation of 'doing the work' is used in the sense common in activist circles, in which, following Audre Lorde, it can include both self-development and more explicitly activist and political labour: every effort to make the world better, personally or publicly.

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[4] Piepzna-Samarasinha, *The Future Is Disabled*, p. 19.
[5] Piepzna-Samarasinha, *The Future Is Disabled*, p. 44.
[6] Piepzna-Samarasinha, *The Future Is Disabled*, p. 22.

This is a different conceptualisation of what ‘work’ is. It has nothing to do with employment; from the more common use of the term, it seeks to retain the sense of importance and value, as well as the effort and difficulty of the activity that is described. In this chapter, I look at the act of dreaming alternative futures and conceptions of human and ecological worth from an ill perspective. I argue that it is closely linked to the concept of ‘work’, whether defined against a certain definition of work or part of efforts to rethink what work could be and the role it plays in society.

This *work of dreaming* is different to other kinds of ‘work’ analysed in this thesis. Whereas the four first chapters of this thesis analyse how illness writers engage with different types of work—creative, administrative, management, and access work—this chapter looks at illness writing that de-centres work as it is currently constructed. As I have argued in the previous chapters, contemporary feminist illness writing often engages with the concept of work to critique it or expand its definition, upsetting normative definitions. Since work is so central to constructions of responsible citizenship in the UK and the US, it may be necessary to claim political status as a worker to gain the legitimacy required to change things. Demonstrating that illness is an active state which in current circumstances requires effort and skill to navigate, is a first step towards questioning what can be done to change this. But ultimately, as I have argued, the texts seek to contribute to a society in which work is not ideologically centred and determining of subjecthood—or, as this chapter will explore, in which work is something radically different from what it is currently considered to be. Could work come to signify meaningful, unalienated activity which is inclusive of different abilities? And how can conceptions of work as defined from ill and disabled points of view contribute to the challenges of navigating an increasingly impaired natural world?

The field of *post-work theory* is concerned with some of these issues. In the formulation of Edward Granter, post-work theory aims 'to transform the way we work, to end work as toil and compulsion, to use our time autonomously and to make society fairer and more decent'.[7] Although the field stretches as far back as Aristotle, much of the current thinking is founded in a Marxist left tradition. Post-work theory has recently undergone a resurgence with the work of, for example, Kathi Weeks, Aaron Bastani, David Frayne, David Graeber, Nick Srnicek and Alex Williams, and Edward Granter, and has had an impact on policy when it comes to the more widespread implementation of four-day work weeks with no reduction in pay. This chapter will look at how illness writing engages with and contributes to this broader intellectual project.

To do so, I take a more expansive approach than in the first four chapters, arguing that engaging with post-work thinking is in fact a mainstay of illness writing. Going back to early examples of the genre, Alice James's (1848-1892) diaries and Virginia Woolf's 'On Being Ill' (1926), I look at how the positionality of illness can contribute to a rethinking of work. Significant for this is engagement with the concept of leisure—not as the opposite of work, but rather in the classical Greek denotation of meaningful activity. From James to Woolf and contemporary feminist illness writing, illness texts imagine societies that support a greater diversity of capacities, abilities, and neurotypes. Elaborating on the entanglement of illness writing and post-work theory, with its intersections in environmentalism,

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[7] Edward Granter, 'Critical Theory and the Post-Work Imaginary', in *Experiencing the New World of Work*, ed. by François-Xavier de Vaujany, Jeremy Aroles, and Karen Dale (Cambridge: Cambridge University Press, 2021), pp. 204–26 (p. 204) <https://doi.org/10.1017/9781108865814.014>.

utopianism, and promotion of leisure, allows for more expansive, constructive, and positive considerations than have occupied the other chapters of the thesis.

In the first section of the chapter, I look at how Woolf's 'On Being Ill', engages with interwar discussions of leisure and the future of work. Specifically, Woolf's arguments about the creative potential of illness can be placed within the context of a contemporaneous discussion around meaningful and non-meaningful activities. The second section of the essay returns to contemporary feminist illness writing. I look at the intersection between environmentalism and chronic illness writing as a particularly rich vein of texts exploring post-work ideas. I focus on a recent co-authored pamphlet, Kaiya Waerea and Jane Hartshorn's *In the Sick Hour* (2020) as well as the texts in the second issue of *Bed Zine* (2021). Exemplary of a recent trend in illness writing, particularly in the UK, these texts merge illness writing with nature (or eco-) writing, considering sustainability and post-work thinking as two sides of the same coin. In the third section, I look at the implications of decentring abled-bodied authorship through collective authorship, 'unfinished' texts, wide citation of chronically ill 'elders' or contemporaries, and the inclusion of textual fragments written in states of severe illness. Using the example of *In the Sick Hour*, my analysis focuses on how shared authorship can be used as a strategy to destabilise individualised development narratives. I argue that the pamphlet uses eco-poetics, collaborative authorship, the inclusion of writing prompts for the readers, and a correspondence section to de-centre the single author and thereby de-centre work practices and timelines designed for the able-bodied. Finally, the last section considers the site of the sick bed as a space for utopian thinking. The bed is traditionally associated with rest and passivity, the inclined position opposed to the active upright of productive, public activity.[8] Chapter 1 complicated this binary, showing the sick bed—as well as the sofa, the bath, and the kitchen chair—as sites of work, creative and activist. This chapter returns to the bed as an active space, but a space for utopian thought and leisure rather than work. I argue that contemporary feminist illness writers should be seen as contributing to post-work thinking, primarily by challenging normative conceptions of work, progressive growth, and experimenting with other, more playful and collaborative types of production.

Alice James' diaries, Virginia Woolf's 'On Being Ill,' and early post-work theory

In 1889, after being made to feel guilty for her constant health problems in Boston and London, Alice James writes about the relief of arriving in Leamington Spa:

> It's rather strange that here, among this robust and sanguine people, I feel not the least shame or degradation at being ill, as I used to at home among the anaemic and the fagged. It comes of course in one way from the conditions being so easy, from the sense of leisure, work reduced to a minimum and the god *Holiday* worshipped so perpetually and effectually by all classes. Then what need to justify one's existence when one is simply one more amid a million of the superfluous?[9]

James' diaries are fascinating explorations of a life intertwined with illness in the late nineteenth century. As discussed in Chapter 2, the diaries document how terminology associated with work and careers was already prevalent in descriptions of illness among the upper middle class at that time. But the diaries do not simply reflect contemporaneous attitudes to illness and work; they challenge prevalent discourses and push into territories of utopian and post-work thinking which are still being explored by illness writers today. In the passage above, James describes how

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[8] Cavarero.

[9] James, *The Diary of Alice James*, p. 36. June 18th, 1889.

the morality ascribed to work creates negative attitudes to illness. James then sets up a utopian representation of Leamington Spa as a negative image to the rushed and overworked masses of the big cities. Leamington Spa becomes a utopian space, a whole alternative universe in which the concept of 'Holiday' replaces work as a deity. With 'work reduced to a minimum,' illness stops being an excluding and distinguishing trait, and James can blend in with 'a million of the superfluous'.

This utopian fantasy cannot be more than loosely based on the Leamington Spa of James' time. But James' insights as expressed in her writing about illness, and her utopian gesture towards a society in which rest is the norm point towards later work, such as Johanna Hedva's suggestion that capitalism will break down if everyone embraces a sick woman identity.[10] It also corresponds to contemporaneous socialist thought, in which rejection of the morality of work and the re-valuing of leisure played a central role. In the essay 'Useful Work versus Useless Toil' (1884), artist and socialist activist William Morris rejected 'the creed of modern morality that all labour is good in itself'.[11] Likewise, in *The Right To Be Lazy* (1881, published in English in 1883), Paul Lafargue, Marxist activist (and Marx's son in law), observed that 'the priests, the economists and the moralists have cast a sacred halo over work'.[12] The purpose of revolutionary socialists as he saw it was to liberate the working classes from the 'religion of work,' and set them free to enjoy abundant leisure time.[13] For the socialists and Marxists at the end of the nineteenth century, the characterisation of work as virtuous primarily served Capital, who could use this

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[10] Hedva, 'Sick Woman Theory'. No pagination.

[11] William Morris, 'Useful Work versus Useless Toil' (1884) <https://www.marxists.org/archive/morris/works/1884/useful.htm> [accessed 9 February 2022].

[12] Paul Lafargue, *The Right To Be Lazy*, trans. by Charles Kerr (Charles Kerr and Co., 1883), Chapter I. <https://www.marxists.org/archive/lafargue/1883/lazy/> [accessed 7 February 2022].

[13] Lafargue, Chapter II.

argument to justify their own pursuit of profit: after all, they were providing jobs.[14] In her description of Leamington as a place in which the 'god *Holiday*' is 'worshipped by all classes,' James subverts this metaphor.

James was not a socialist, but she was undoubtedly exposed to some socialist thinking through her voracious reading and by her father. Her father, Henry James (1811-1882), was critical of the materialism of American society and interested in ideas of communal living and the utopian socialism of the French philosopher Charles Fourier.[15] While a controversial figure, Fourier is often described as a foundational thinker of 'the end of work', pronouncing the majority of work in his time 'profitless boredom'.[16] Fourier argued that society should be restructured; away from work as profit-creation for capital and toward the necessary work being allocated according to passions and interests. The confluences between James' politically invested writing about illness and utopian socialist thinkers like Morris, Lafargue, and Fourier show that in the late nineteenth century, ill and leftist political writers already had shared objectives relating to criticising a dominant discourse of work. In her illness writing, James engages with this political thinking when she connects the ideological critique of work to the destigmatisation of illness.

Some historians of labour point to classical Greece as a historical example of a society in which citizens lived a work-free life (all work being carried out by

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[14] Morris. Marx saw unalienated labour, such as in the example of the craftsman, as the highest expression of humanity. However, at the end of the nineteenth century, most jobs were defined by alienation and exploitation, they argued, which made the characterisation of work *in and of itself* virtuous problematic. Karl Marx, 'Economic and Philosophical Manuscripts', in *Early Writings*, ed. by Lucio Colletti, trans. by Gregor Benton and Rodney Livingstone, Reprint edition (London: Penguin Classics, 1992), pp. 279–400.

[15] William Hall Brock, 'Phalanx on a Hill: Responses to Fourierism in the Transcendentalist Circle' (Loyola University Chicago, 1995), p. 6.

[16] Granter, p. 207; Charles Fourier, *The Utopian Vision of Charles Fourier*, trans. by J. Beecher and R. Bienvenu (London: Jonathan Cape, 1972), p. 148.

enslaved people).[17] However, what is now commonly comprised under the header of 'post-work theory' was founded in the mid-nineteenth century with the writings of Marx, Lafargue, Fourier and others.[18] Drawing on a host of different thinkers, Marx contrasted the alienated work carried out in workhouses and factories with earlier, pre-industrial and 'pre-technological' ways of working.[19] He argued that productive activity was the most important way for humans to express themselves and live in relation to the world, but that many current jobs eschewed the creativity, autonomy, skill, and material community that was the basis of making this activity meaningful.[20] While problematising the use of technology when it forced workers to bend their bodies to the machines, Marx looked positively at the possibility for technology to take over whole swathes of production, and free workers to take on more meaningful activities of their choice.[21] Alongside the opposition between work and leisure, Marxist and socialist thinkers were envisioning a future in which automation would reduce working hours for all, and reinstate leisure as the primary means of finding meaning.

Cultural historians point to the latter half of the nineteenth century as the point at which the (fraught) concept of leisure we have today was starting to develop.[22] By the time Woolf wrote 'On Being Ill' (1926), leisure was at the centre of national debates about post-war community reconstruction, and these, as I will

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[17] Herbert Applebaum, *The Concept of Work: Ancient, Medieval, and Modern* (Albany: State University of New York Press, 1992).
[18] Granter, p. 208; William James Booth, 'Economies of Time: On the Idea of Time in Marx's Political Economy', *Political Theory*, 19.1 (1991), 205–22.
[19] Daniel McLean and Amy Hurd, *Kraus' Recreation and Leisure in Modern Society* (Burlington: Jones and Bartlett Publishers, 2014), p. 50.
[20] Marx, 'Economic and Philosophical Manuscripts'.
[21] Karl Marx and Ernest Mandel, *Capital: A Critique of Political Economy, Vol. 3*, trans. by David Fernbach (New York: Penguin Classics, 1993).
[22] Peter Burke, 'The Invention of Leisure in Early Modern Europe', *Past & Present*, 146.1 (1995), 136–50; Robert Snape, *Leisure, Voluntary Action and Social Change in Britain, 1880-1939* (Bloomsbury, 2018).

show, inform the text's arguments related to illness. 'On Being Ill' is most famous for its argument about the creative potential of illness. Woolf describes illness as bringing 'tremendous spiritual change', and 'astonishing' insight into the geography of the soul, revealing 'undiscovered countries,' 'wastes and deserts,' and 'precipices and lawns sprinkled with bright flowers'.[23] With this richness, Woolf writes, it is 'strange indeed that illness has not taken its place with love, battle and jealousy among the prime themes of literature'.[24] The explanation, she argues, is that the language of illness has been too limited, and that illness warrants a new poetics.

Alongside this argument also runs another thematic strain to which Woolf arguably dedicates even more space: the status of illness in the public consciousness. Woolf ties this to a discussion around 'use,' leisure, and creative labour. The essay contrasts two primary images, both of which can be found in a central passage:

> in health the genial pretence must be kept up and the effort renewed—to communicate, to civilise, to share, to cultivate the desert, educate the native, to work together by day and by night to sport. In illness this make-believe ceases. Directly the bed is called for, or, sunk deep among pillows in one chair, we raise our feet even an inch above the ground on another, we cease to be soldiers in the army of the upright; we become deserters. They march to battle. We float with the sticks on the stream; helter-skelter with the dead leaves on the lawn, irresponsible and disinterested and able, perhaps for the first time for years, to look round, to look up – to look, for example, at the sky.[25]

The healthy person is a worker; a part of the 'army of the upright,' advancing a 'make-believe' imperialist and colonialist project of national productivity. The recumbent ill person, by contrast, floats 'helter-skelter,' closer to nature and able to access a more authentic perspective on the world. Here and elsewhere, Woolf places illness beyond a supposed binary of work and leisure. The perspective granted by illness allows the ill person to see through not only the pretence of the world of

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[23] Woolf, p. 32.
[24] Woolf, p. 32.
[25] Woolf, pp. 36–37.

work, but also of contemporary constructions of leisure: the impetus ‘to work together by day and by night to sport’. In illness, the narrator argues, ‘the world has changed its shape; the tools of business grown remote; the sounds of festival become romantic like a merry-go-round heard across far fields’.[26] In this image, illness is at a distance from both work and leisure activities like the festival, neither fully within reach.

This opposition between work and leisure which Woolf places the ill person beyond was contested at the time. Leisure was changing from a wealthy lifestyle only accessible to the Victorian middle and upper classes (also known as *the leisure class*), to something which was seen as a right for all.[27] The second half of the nineteenth century saw a change in ideas of leisure from an earlier conception as a meaningful, abstract sense-making undertaken by certain classes, to something that was more strongly defined by not being ‘work’. Workers started organising in protest of the industrial workplace, with labour movements fighting for better working conditions and shorter hours. Among these demands, the right to leisure was central, as demonstrated in the primary slogan ‘8 hours work, 8 hours rest, 8 hours for what we will’.[28] As this slogan emphasises, leisure is not rest, but something that is equally important.

Leisure was seen as something which was earned through work. This right to leisure shaped, as Helen Meller and Jose Harris have shown, efforts to promote urban civic communities following the First World War.[29] Politically, this was encouraged on the basis of wartime surveys showing that disability, illness, and bad

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[26] Woolf, p. 34.

[27] Thorstein Veblen, *The Theory of the Leisure Class* (Macmillan, 1899); Snape.

[28] Robert Whaples, ‘Winning the Eight-Hour Day, 1909–1919’, *The Journal of Economic History*, 50.2 (1990), 393–406.

[29] Helen Meller, *Leisure and the Changing City 1870 - 1914* (London: Routledge, 1976); Jose Harris, *Private Lives, Public Spirit: Britain: 1870-1914* (London; New York: Penguin Books, 1995).

physical illness resulting from poverty and bad working conditions impacted the ‘quality’ of British soldiers. In 1919, the National Council of Social Service held its first conference, entitled ‘The Leisure of the People’, placing the construction of community centres and shared forms of leisure activity for citizens as central to post-war reconstruction and the early development of the welfare state.[30] As Regina Martin writes, drawing on the work of Harold Perkin: ‘the leisure that was characteristic of the feudal ruling classes, which had shaped the horizon of desires for the bourgeoisie, ceases to exert its hegemonic appeal as the professional classes grow in size and influence and non-manual labor becomes the idealized form of work’.[31] The political power of the working class fundamentally changed conceptions of leisure, making it more widely available but also bound up with ideological projects of national improvement. The welfare state promoted leisure, especially when related to sports and community activities, as a way of supporting the development of a strong, cohesive workforce and a potential future wartime effort.

Like Marx, Morris and Lafargue, Britain’s preeminent economists at the time, Bertrand Russell and John Maynard Keynes, thought that while some work needed to be undertaken for society to function, much current work could be easily abolished, particularly with the development of technology and increasing automation. They agreed that work had the possibility of being a means through which humans could express themselves at the highest level, but argued that this was not the case in most jobs at the time. As Russell writes in the essay ‘In Praise of Idleness’ (1932), building on ideas he had been developing over the previous

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[30] Snape, pp. 89–110.

[31] Regina Martin, ‘Speculating Subjects: Keynes, Woolf, and Finance Capitalism’, *Modern Language Studies*, 47.1 (2017), 10–25 (p. 17).

decades: ‘I think that there is far too much work done in the world, that immense harm is caused by the belief that work is virtuous’.[32] By letting the interest of capital control the market, he writes:

> we produce hosts of things that are not wanted. We keep a large percentage of the working population idle because we can dispense with their labor by making others overwork. When all these methods prove inadequate we have a war: we cause a number of people to manufacture high explosives, and a number of others to explode them, as if we were children who had just discovered fireworks. By a combination of all these devices we manage, though with difficulty, to keep alive the notion that a great deal of manual work must be the lot of the average man.[33]
>
> Modern methods of production have given us the possibility of ease and security for all; we have chosen instead to have overwork for some and starvation for others. Hitherto we have continued to be as energetic as we were before there were machines. In this we have been foolish, but there is no reason to go on being foolish for ever.[34]

His proposed solution was effectively the same as that of by Morris and Lafargue: a maximum of 4 hours of civic duty work per day (to be minimised as technology permits), leaving ample time for leisure.

Russell argues that his proposed workday of maximum four hours would not only change the way people go about their work, but also the way they spend their leisure time. ‘Since men will not be tired in their spare time, they will not demand only such amusements as are passive and vapid’; instead, everyone would be able to indulge their interests, whether it be painting, writing, science—or even economics or government.[35] Each of these activities would provide personal fulfilment and also benefit society. That economics or government are better suited as hobbies than professions, Russell explains, is because they would then be undertaken by people with a real interest in society, possessing the time ‘to develop their ideas without the

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[32] Bertrand Russell, ‘In Praise of Idleness’, *Harper’s Magazine*, 1 October 1932 <https://harpers.org/archive/1932/10/in-praise-of-idleness/> [accessed 9 February 2022]. No pagination.

[33] Russell.

[34] Russell.

[35] Russell.

academic detachment that makes the work of university economists lacking in reality'.[36] This idea has much in common with the current activist concept of 'doing the work' but Russell specifically codes it through the idea of leisure rather than work.

Woolf's fellow Bloomsbury Group thinker Keynes had been working on similar ideas. In the essay 'Economic Possibilities for Our Grandchildren,' published in the essay collection *Essays in Persuasion* in 1930, he argues that developing a new conception of leisure is one of the most pressing challenges facing humanity. Economic growth and automation, he argued, were enabling—and had the possibility to enable many more people soon—to live lives in which work played a minimal role. But to access this future, political valuations of work and leisure needed to shift away from the belief that work was healthy for the population. Entering a public discussion at the time about the middle-class housewives who had enough money to hire staff to manage housework and childcare but who suffered 'nervous breakdowns' in disproportionate numbers, Keynes rejected the prevalent view that this was proof that inactivity was unhealthy. Instead, he argued that it was the pathologisation of inactivity which had foreclosed meaningful models of leisurely existence for the middle and lower classes.[37] This, he argued, needed to change; imagining meaningful lives without work at their centre was paramount for building a good society. 'Thus for the first time since his creation man will be faced with his real, his permanent problem,' Keynes wrote: 'how to use his freedom from pressing economic cares, how to occupy the leisure, which science and compound interest will have won for him, to live wisely and agreeably and well'.[38]

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[36] Russell.
[37] John Maynard Keynes, 'Economic Possibilities for Our Grandchildren', in *Essays in Persuasion* (New York: W. W. Norton & Company, 1963), pp. 358–73.
[38] Keynes.

At a time when the promotion of leisure was at the centre of national public health policy, both Russell and Keynes sought to return to an older conception of leisure more in line with classical Greek thought. Plato and Aristotle shared an understanding of leisure (*scholê*) as 'freedom from material necessity, which allows the right kind of individual to achieve virtue, human flourishing (*eudaimonia*) and the higher ends that a (but not every) human being is capable of'.[39] Leisure was contrasted with 'occupation' (*ascholia*) which primarily referred to manual labour. The Greek conception of leisure was deeply classist and essentialist—Plato and Aristotle believed that only those born with the faculties for abstract thinking could participate in leisure, and thereby attain true human flourishing and virtue. However, their conceptualisation was taken up as useful because it did not contrast leisure with work. The Greeks instead saw the two as continuous; work, or 'activity', was divided into different subcategories, the highest and most meaningful type being leisure.[40] This is the source of the still-extant understanding of leisure as not simply the absence of work (time off), but a deliberate and meaningful activity, undertaken for pleasure alone. Keynes' and Russell's arguments that creative endeavours such as painting and writing be placed with science, government, and economics in a category of activities undertaken to make life meaningful, effectively recover the Greek understanding of leisure. If the necessary work (*ascholia*) was distributed equally, everyone would be able to undertake the leisure activities (*scholê*) of their choice, and thereby thrive.

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[39] Thanassis Samaras, 'Leisure in Classical Greek Philosophy', in *The Palgrave Handbook of Leisure*, ed. by Karl Spracklen and others (London: Palgrave Macmillan, 2017), pp. 229–48 (p. 229).
[40] Samaras.

Critics have demonstrated that Woolf and Keynes were interlocutors, which influenced the writings of both.[41] While Woolf would go on to write those of her works that deal most explicitly with economics, *A Room of One's Own* (1929), *Three Guineas* (1938), and *Between the Acts* (1941), at the time of writing 'On Being Ill' she had already shown this interest in *Night and Day* (1919). I argue that 'On Being Ill' should be included among those of Woolf's texts that engage with economic thought. In 'On Being Ill', Woolf proposes a model of being in which illness, stillness, and the lack of unnecessary work take precedence. Woolf writes that 'with the heroism of the ant or the bee […] the army of the upright marches to battle. Mrs. Jones catches her train. Mr. Smith mends his motor'.[42] She is thus attentive to the ways in which ideals of 'heroism' are intertwined with both work and wartime effort, imbricated with a national project of productivity. In contrast to this, Woolf proposes that being ill affords a different perspective, characterised by seeing the small and near. In illness, for example, flowers take on a new significance:

> Let us examine the rose. We have seen it so often flowering in bowls, connected it so often with beauty in its prime, that we have forgotten how it stands, still and steady, throughout an entire afternoon in the earth. It preserves a demeanour of perfect dignity and self-possession. The suffusion of its petals is of inimitable rightness. Now perhaps one deliberately falls; now all the flowers, the voluptuous purple, the creamy […]; gladioli; dahlias; lilies, sacerdotal, ecclesiastical […] all gently incline their heads to the breeze.[43]

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[41] Evelyn T. Chan, 'A Balancing Act: Specialization in "Between the Acts"', *Woolf Studies Annual*, 18 (2012), 29–52; Alice Keane, '"Full of Experiments and Reforms": Virginia Woolf, John Maynard Keynes, and the Impossibility of Economic Modeling', in *Interdisciplinary/Multidisciplinary Woolf*, ed. by Ann Martin and Kathryn Holland (Liverpool; Clemson: Liverpool University Press; Clemson University Digital Press, 2013), pp. 20–26; Jane Goldman, 'Case Study: Bloomsbury's Pacifist Aesthetics: Woolf, Keynes, Rodker', in *The Handbook to the Bloomsbury Group*, ed. by Derek Ryan and Stephen Ross (London: Bloomsbury Academic, 2018), pp. 294–308; Martin; Jennifer Wicke, 'Mrs. Dalloway Goes to Market: Woolf, Keynes, and Modern Markets', *Novel: A Forum on Fiction*, 28.1 (1994), 5–23; Jacqueline Rose, 'Virginia Woolf and the Death of Modernism', *Raritan*, 18.2 (1998), 1–18.

[42] Woolf, p. 38.

[43] Woolf, p. 38.

Woolf praises flowers for their indifference to humans, and the lesson they carry as a memento mori and a reminder of our own inconsequence. 'It is only the recumbent who know what, after all, nature is at no pains to conceal—that she in the end will conquer; the heat will leave the world'.[44] Within this knowledge lies an alternative story about the value of life, which the recumbent can glean from the flower and the sky: the importance of beauty and stillness in the face of inevitable doom. Always pressing forward has little reason from this perspective, and the ill point of view thus problematises the forward march associated with workers.

It is hard not to see this paragraph as an agnostic gloss on a Biblical passage, Luke 12:27: ‘Consider the lilies how they grow: they toil not, they spin not; and yet I say unto you, that Solomon in all his glory was not arrayed like one of these’.[45] In this passage, Jesus warns his disciples that obsession with material goods and the constant drive to have more and be richer distracts people from understanding the true meaning of life. In the Christian interpretation, it means that God will provide for the faithful and that they therefore do not need to prove themselves through pursuit of material wealth or tiresome work. This passage became emblematic of ideas about the importance of leisure over work, with Keynes also using this passage to support his model of leisure at the centre of human purpose. The outcomes of the Greek conception of leisure, as Keynes explains it, are a focus on the present rather than the future, and a new appreciation of beauty over ‘usefulness’:

> those walk most truly in the paths of virtue and sane wisdom who take least thought for the morrow. We shall once more value ends above means and prefer the good to the useful. We shall honour those who can teach us how to pluck the hour and the day virtuously and well, the delightful people who are capable of taking direct enjoyment in things, the lilies of the field who toil not, neither do they spin.[46]

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[44] Woolf, p. 39.
[45] King James Bible, Luke 12:27.
[46] Keynes.

While these passages distinguish between 'better' and 'worse' types of leisure, implying that certain activities are more meaningful than others, they still formulate alternatives to the idealisation of employed work. Although writing in secular contexts, Woolf and Keynes nod to the Biblical passage by taking up the image of flowers to express the inherent dignity of the human being, as separate from accolades earned through work. The idea of 'sane wisdom,' however, will contrast strongly with contemporary conceptions of 'crip' wisdom and knowledge as elaborated in later sections of this chapter.

There are other aspects which more closely chime with contemporary thinking on the subject. Woolf suggests that in illness we 'become as the leaf or the daisy, lying recumbent', present in the world through stillness. Similarly to Keynes, Woolf presents the imperial project of national productivity, 'to conquer the desert, to educate the native' as unsustainable, leading, as only the ill person really understands, to inevitable defeat: 'stiff with frost we shall cease to drag our feet about the fields; ice will lie thick upon factory and engine; the sun will go out'.[47] But the flower, 'thrusting its head up undaunted in the starlight' long after all human life has been eradicated, contains a glimmer of hope for a more sustainable form of life.[48] In line with much later eco-critical and environmentalist writing, Woolf thus presents a dystopian vision of the extinction of humanity as well as an alternative model of value, which explicitly sets up parallels between the properties of illness and a more natural pace and circularity.

Looking at *Three Guineas* and *Between the Acts*, Alice Keane observes that the influence between Woolf and Keynes is particularly pronounced in the way that

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[47] Woolf, p. 37.
[48] Woolf, p. 37.

they ‘conceive of economic goals not as ends in themselves but as a basis for the production of art and the achievement of the good life’.[49] Like Keynes, Woolf uses attention to beauty as an exemplary form of paying attention to present sensations. They both valorise a form of moving through time that is flexible rather than driven towards a specific purpose. The sick person is ‘floating’ and able to ‘look round’ rather than ‘marching’ towards a far-off objective. Her attention is ‘sudden, fitful, intense’, ‘disinclined for the long campaigns that prose exacts,’ but suited to the short beauty found in lines of poetry.[50] The flowers express the presence of aesthetic value for its own sake and the suggestion that the alternative to work is not rest, but beauty. While Woolf’s text is not a political manifesto for leisure in the way of Keynes’ text, her essay contributes to a similar exploration of states that form alternatives to normative ideals of labour. She is interested in the affordances of stillness, recumbence, and attentiveness to the frivolous, the beautiful and the sensations of the body; in finding value in what is normally dismissed as unproductive.

Peter Fifield points to the utopian thinking of ‘On Being Ill’, which he observes participates in a specific configuration of the artist as visionary:

> This is a utopian gesture on Woolf’s part, then, where the ill are not only rescued from being financial and emotional drains on a healthy society—those descriptions often given by the suspicious, the unsympathetic, and the statistically-minded—but rehabilitated into a populace that would see the invalid as a specialist able to undertake the labour that cannot be done by those who remain productive and mobile. Illness, then, is no longer an inconvenience, a social ill, or even, paradoxically, an individual pain. Rather it is an opportunity for shared insight and creativity. Ill health becomes a sign of authorial vocation where the writer and the invalid merge: set apart in order to dream of wonderful things.[51]

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[49] Keane, p. 20.

[50] Woolf, p. 40.

[51] Peter Fifield, *Modernism and Physical Illness: Sick Books* (Oxford, New York: Oxford University Press, 2020), p. 11.

In describing this particular form of dreaming as a type of labour specialised to those who are ill—a type of 'labour that cannot be done by those who remain productive and mobile'—Fifield demonstrates how the *work of dreaming* is already a key concern of one of the founding texts of the genre of illness writing. As described in the introduction to this chapter, Piepzna-Samarasinha claims a similar prophetic societal role for those who are chronically ill or disabled, as voices for a 'shared insight' and collective authors of dreams which may help improve society for everyone.

However, as Fifield shows, comparing 'On Being Ill' with Woolf's diaries and letters presents a more complex story about her relationship to illness and its affordances for creative work. Woolf sometimes describes illness as she presents it in 'On Being Ill', as creative fuel; but just as often, she describes how illnesses leave her unable to write for weeks at a time. Her novels, Fifield demonstrates,

> show illness to be powerfully destructive and socially limiting. Rather than providing a reliable lens that bestows powerful insight and creative resources for the sufferer, it more often institutes the severing of intimate relationships, the elimination of insight, and an emboldened gaze that examines the invalid as a spectacle rather than empowers them as a sage.[52]

With her nuanced engagements with illness elsewhere in her oeuvre in mind, 'On Being Ill' stands out for its wholly positive representation of illness as a source of artistic inspiration. However, if we read the essay as participating in a late 1920s discussion which seeks to re-value states commonly seen as 'not-doing'—whether illness, leisure, or creative work—this would explain the one-sidedness of the essay. Keynes writes that while the leisure society is some way off (up to a century away), the present is a time for starting to prepare for this destiny, 'in encouraging, and

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[52] Fifield, p. 110.

experimenting in, the arts of life as well as the activities of purpose'.[53] 'On Being Ill' leads the way for Keynes' text in being one such experiment.

The 1920s and early 1930s saw a renewed interest in leisure, ecology, and new conceptions of work, developed against a background of crisis. The Bloomsbury Group and other groupings of the philosophical and economical milieu including Russell responded to post-war reconstruction efforts championing a particular set of values around work and leisure. With their texts decentring work, they intervened in the discussion, arguing for using the moments following crisis (the war, the Wall Street Crash of 1929) as times to build an ideological foundation for a society in which purpose is geared towards the 'arts of life'. Similarly, the current wave of post-work thinking has been built on a background of crisis. In the US and the UK, the consequences of ongoing climate crisis, growing inequality, and an increase in the part of the population in precarious jobs underline the necessity of building more sustainable work practices. Much of the recent post-work thinking has been developed after the financial crisis of 2008, often described as the death of neoliberalism and the unwavering belief in the free market, as states resorted to large-scale diversion of public funds to bail out financial institutions.[54] Moreover, a mainstream interest in post-work thinking has arisen alongside the Covid-19 pandemic and the attendant changes brought about in work cultures, something to which I will return at the end of this chapter.

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[53] Keynes, p. 373.

[54] Sitaraman; Aalbers.

Sustainable thinking

James' and Woolf's texts show that illness texts have engaged with an intellectual project of post-work thinking going back at least a century and a half. While more recent illness writing responds to new generations of post-work thinking, the re-valuing of supposed 'inactivity' as well as a return to nature for more sustainable conceptions of being remain key themes. The interest in working and doing less can also be seen in recent manifestos which have gained popular acclaim, such as Jenny Odell's *How to Do Nothing: Resisting the Attention Economy* (2019) and Tricia Hersey's *Rest Is Resistance: A Manifesto* (2022).[55] The idealisation of slowing down can also be recognised in concepts like *slow fashion* and *slow food*—trends and social movements—and the increased interest in mindfulness and meditation.

In chronic illness writing, Elisabeth Tova Bailey's memoir of ME/CFS and mitochondrial disease, *The Sound of a Wild Snail Eating* (2010), finds an alternative model for life in the slow movements of a wild snail who lives in a terrarium by the narrator's bedside. Biologist and writer Eva Saulitis' posthumously published memoirs of terminal illness, the essay collection *Becoming Earth* (2016), also draws its lesson for how to live and die from an alternative temporal scale found in nature: a mountain which remains still, even as flowers bloom and wither on it with the changing seasons. The book advises readers to live in the present rather than chase material success and concludes with the words: 'there is a future, and it is not us. It is the mountain. It is the earth'.[56] This environmental preoccupation is closely related to texts proposing that the experience of chronic illness creates knowledge useful in a future which needs to contend with climate catastrophe.

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[55] Jenny Odell, *How to Do Nothing: Resisting the Attention Economy* (Brooklyn, NY: Melville House, 2019); Tricia Hersey, *Rest Is Resistance: A Manifesto* (New York: Little, Brown Spark, 2022).
[56] Eva Saulitis, *Becoming Earth: Essays* (Pasadena, CA: Boreal Books, 2016), p. 130.

In Christine Miserandino's influential blog post 'Spoon Theory' from 2003, the position of chronic illness is posited as one defined by the need to conserve energy, with the ill person 'having to make choices or to consciously think about things when the rest of the world doesn't have to'.[57] Hedva echoes this sentiment, writing 'for those without chronic illness, you can spend and spend without consequence: the cost is not a problem. For those of us with limited funds, we have to ration, we have a limited supply: we often run out before lunch'.[58] Having limited resources applies to the ill person but also defines a world in climate crisis. Maggie Foster, another chronically ill writer, elaborates this connection, proposing the ill person's expertise in conserving limited resources and in accepting doing less as a necessary corrective to capitalist ideals of constant growth. She writes:

> the world needs us for what's to come, because we know something about being destroyed by the world [...] and if you want to know about the deep strength of that you have to have the courage to be in that slowness, that anxiety, that temporality that doesn't run smoothly alongside all the things we think are supposed to happen in life. A temporality that doesn't make sense in the world we have, but might be necessary in the one we want.[59]

The experience of illness holds the strength to cope with disaster, but also opens the door to new imaginaries for a more desirable and equal society. This is a more positive vision than that imagined by Kelly Davio, who humorously suggests that due to their forethought and ability to conserve resources, 'sick girls will outlive everyone in the coming zombie apocalypse'.[60]

These texts reinforce arguments championed by post-work thinkers like Russell and Marcuse that a large part of the need to work is driven by unreasonably

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[57] Christine Miserandino, 'The Spoon Theory', *But You Don't Look Sick*, 2003 <https://butyoudontlooksick.com/articles/written-by-christine/the-spoon-theory/> [accessed 30 September 2019].
[58] Hedva, 'Sick Woman Theory'
[59] Maggie Foster, 'My Awkward In-Pain Self', *Mask Magazine*, 'The Not Again Issue', 2016.
[60] Davio, p. 80.

high consumption, a so-called ‘false need’.[61] A chronically ill person’s ‘relentless rationing of energy’ can provide an alternative, sparse economy as a counterpoint to ever-growing consumption. The chronically ill person holds this knowledge but looking at the texts, they often learn it by closely observing nature. In *The Undying* (2019), Anne Boyer considers ‘*mutilated body as ecopoetic*’ as a subtitle for the text. The final product ends up with a snake on the cover; a different signifier to Bailey’s snail, but nonetheless an image from the natural world: an animal symbolising medicine, circular temporality, and rebirth through the shedding of successive skins. Likewise, British poet Polly Atkin draws on the history of nature writing as a framework for writing about chronic illness, such as in *Much With Body* (2021). In her poems, nature and chronic pain encroach on the body in parallel, and the solution to both is to give over to them, relinquishing the desire to control the natural world and the body.

Disability activist and theorist Sunaura Taylor combines ill and disabled knowledge and the environmental movement in the concept of ‘disabled ecologies’.[62] Taylor elaborates the connection between human bodies and the environment, observing how discourses of sickness and disability are increasingly applied to damage to ecosystems. Both the body and ecosystems are defined in relation to their productivity. ‘Looking closely at how different eco systems are defined as impaired,’ Taylor argues, ‘we find that as with legislative definitions of human disability in the United States, it is the inability to work, to be able to labour and produce capital, that shapes definitions of impairment’.[63] In an age of mass

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[61] Herbert Marcuse, *One-Dimensional Man: Studies in the Ideology of Advanced Industrial Society*, 1st edition (London: Routledge, 2002), p. 5.

[62] *Keynote Lecture by Sunaura Taylor: Disabled Ecologies: Living with Impaired Landscapes*, dir. by Art Windsor-Essex, 2022 <https://www.youtube.com/watch?v=JXTvQvDdYS8> [accessed 8 February 2023].

[63] *Keynote Lecture by Sunaura Taylor*, loc. 38:20.

disability and impairment, she argues that ill and disabled people hold knowledge that already is, and will increasingly be, critical to life under climate change:

> If our ecosystems are ill, impaired, and disabled, then it seems clear that turning to disabled and ill people for the critical and generative understandings of health, limitation, woundedness, loss, and adaptation and care that have emerged from the communities is vital. Critical disability perspectives show that with access to healthcare, social support, and community, disabled life can be not only liveable but flourishing. They insist that while damage is real, it is also a source of ethical insight, of value, and creativity.[64]

The emphasis on building a life that is not 'not only liveable but flourishing' and which holds 'creativity' in particular, subverts medical and political representations of impairment as always second grade to the ideal of bodily health. By convincingly arguing that impairment is already the norm, Taylor changes the discussion, going away from climate change as a hypothetical, dystopian future and embedding us in the now, when it is already happening.

Images of ill and disabled flourishing, Taylor argues, can provide a counterpoint to fatalistic fears, showing the importance of focusing on adapting and mitigating in the present through the building of communities, networks of support, and more sustainable value systems. Flourishing is exactly what post-work thinkers argue that the current reality of work limits. A key argument in post-work thinking, more recently advanced by André Gorz and David Frayne, is that work must be displaced from its ideological and moral status before it is possible for alternative, better constructions of society to take place.

Utopian thinking allows for radical visions in which this takes place. Illness writing has a rich tradition of imagining societies in which health and work are de-centred and replaced with illness and unemployment. In the title essay of Bellamy's *When the Sick Rule the World* (2015), the narrator weaves an account of going to a

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[64] *Keynote Lecture by Sunaura Taylor*, loc. 39:31.

meeting for people with the contested condition Multiple Chemical Intolerance together with vignettes of people she meets there. The vignettes describe the difficulties of living with a contested and invisible condition, using characters such as the former psychologist ‘sick Nina’, whose illness has not only made her unemployed and homeless, but also prevented her from staying in the chemically contaminated homelessness shelters.[65] Illness rules Nina’s life, as emphasised by ‘sick’ being used as an epithet for her name, and the contested condition places her outside even the sparse existing support options. Over the course of the essay, the narrative increasingly starts exploring utopian imaginations for a future in which current hierarchies of illness and health are reversed. The narrator imagines that ‘when the sick rule the world the well will be servants, and all the well will try to become sick so they too can have servants’.[66] Similarly, it is wellness that is marked as divergent; in this future world, ‘the sick refer to people who do not wear gasmasks as “breathers”’.[67]

Several of the imagined scenarios for a world in which illness is centred does away with types of work with a high degree of precarious labour such as the hospitality sector. The narrator states: ‘When we eat in a restaurant we take in the energy of those who cook and serve, and their energy is bad energy. When the sick rule the world there will be no restaurants’.[68] The utopian society is one in which collectivity rules:

> The sick will create new families based not on blood but affinity of symptoms. The sick will travel in packs commandeering porcelain-lined fragrance-free buses. The well will no longer delete the email of the sick. When the sick rule the world hotel rooms will be obsolete, airplanes will be obsolete, new cars will be obsolete.[69]

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[65] Bellamy, p. 33.
[66] Bellamy, p. 35.
[67] Bellamy, p. 31.
[68] Bellamy, p. 34.
[69] Bellamy, p. 30.

Public transportation replaces individual cars; new family formations appear; the constant production of new consumer goods is replaced by better-quality, long-lasting products; long-haul travel ends, with communities staying local. This is a world in which both jobs and leisure are configured differently from how they are now.

The essay is surrealist in the sense that the imagined world does not add up. The objective is not to construct an alternative, internally coherent world. Instead, the reversals are effective in defamiliarizing the contemporary world, exposing a current logic that is equally inconsistent. Utopianism doesn't need to have actionable steps; as Granter reminds us, 'it is possible to imagine a world without work, independently of whether one accurately predicts that this will actually come to pass'.[70] Indeed, the imagination can be crucial for challenging assumptions about desirability of the status quo. Kathi Weeks describes the vision of a life 'no longer subordinate to work' as one that can pave the way for 'new theoretical vistas and terrains of struggle. The point is that these utopian demands can serve to generate political effects'.[71]

Jane Hartshorn and Kaiya Waerea's pamphlet *In the Sick Hour* (2020) brings together these themes and arguments with alternative ways of working. Written and published during the covid-19 pandemic, the pamphlet reflects on chronic illness and social isolation. The last poem in the pamphlet draws on Bellamy's utopian vision of a society designed around the needs of the ill. The poem, 'After Dodie Bellamy's When the Sick Rule the World (Toward a Crip Futurity!)', adopts Bellamy's repeated sentence structure. Starting with the sentence 'when the sick rule the world,

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[70] Granter, p. 217.
[71] Weeks, p. 221.

my emails will contain no apologies', the poem goes on to suggest something like a socialist economy with the state-controlled production of items: 'there will only be one option for each food item – good quality and affordably priced in minimal packaging'.[72]

Sustainability, equality, and a reduced need to make choices go hand in hand in this imagined future. The poem points out that energy is required by making choices that are artificially produced to create profit. They also extend this observation to harassment and prejudice, describing how much energy could be saved if there was less prejudice and discrimination:

> when the sick are feeling up to taking a walk down the street, no
> energy will be wasted avoiding cat callers and street harassers. No
> one will tell the sick to cheer up, or to smile. Those who might
> otherwise have done so will be at home, safe and well fed, reading
> crip-feminist literature.[73]

This partially invokes a social model of disability; ill people not only have less energy to begin with, but the prejudice they meet further deplete them. Moreover, the fact that the two first lines in this verse end on the word 'no' emphasises the need for negation before a more equal future can be built.

The pamphlet returns to ideas of 'crip time'. In the utopian vision, things are scheduled around ill people's energy levels: 'When the sick rule the world, things won't be missed, cancelled, delayed, postponed – just moved to support the sick body'.[74] This concept is further expanded on in the e-mail correspondence placed at the end of the pamphlet. This is another example of ill writers including e-mail in a literary text. In a similar way to Hedva's essay analysed in Chapter 4, Hartshorn and

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[72] Kaiya Waerea and Jane Hartshorn, *In the Sick Hour* (London: Takeaway Press, 2020). No pagination.
[73] Waerea and Hartshorn.
[74] Waerea and Hartshorn.

Waerea insert the e-mails as a way of re-using labour already done, recycling labour rather than producing something new. This formally re-enacts a more cyclical and sustainable mode of production. The e-mails also provide a view into the writing process behind the finished text. In the manner of the metatextual description of the embodied situation of writing as analysed in Chapter 1, the e-mails exchanged during the writing process emphasise the status of the text as a constructed, laboured-over object and draws attention to the writers' positionalities.

In the 'Correspondence' section, Waerea writes about a 'reorientation to time […] through illness'.[75] The ill body's needs are not provided for by 'the homogenized spaces – of marketised higher education, workplaces, even of modern-industrial medicine' with their deadlines and normative timelines. She quotes Alison Kafer's description of 'crip time' as an alternative to normative time:

> Crip time is flex time not just expanded but exploded…a challenging to normative and normalising expectations of pace and scheduling. Rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds.[76]

The pamphlet enacts this in practice through its illustrations of non-linear timelines and formations (spirals, rhizomes, circles) and poems entitled 'Time' A to E, each with a different experimental structure. Moreover, a series of poems entitled 'Bed Rest' I-VI is dispersed throughout the poetry section of the pamphlet. In the 'Correspondence' section, Hartshorn describes these as poems that 'are interspersed throughout the other poems as moments of arrested time, that refuse to let the reader experience linear time, and instead, drag them back again and again to moments of stasis'.[77]

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[75] Waerea and Hartshorn.

[76] Alison Kafer, *Feminist, Queer, Crip* (Bloomington, Indiana: Indiana University Press, 2013). Qtd. in Waerea and Hartshorn.

[77] Waerea and Hartshorn.

The ‘Bed Rest’ poems echo Woolf’s image of the recumbent perspective of the ill person as facilitating a closer attention to nature, and with it an alternative model of meaningful pursuit. A particular connection with animals and nature is elaborated in these poems. Nature intrudes into the sick bed, dissolving boundaries between the sick body and the outside world, such as in ‘Bed Rest II’ when the narrator’s mother brings a pair of wet trainers into the room. ‘Spotting my sheets with dark spores, which / grow little arms and legs that wiggle and hook / together, moving quickly across my skin like / the crisp lacework of a surgical dressing’.[78] Even though the speaker is isolated inside in her room, she encounters the natural world. While the spores multiplying could have become a nightmarish image of contamination, the comparison with surgical dressing instead indicates that there is safety and protection to be found in the enmeshment with other natural organisms. The dark spores grow arms which hook together, not trapping the narrator, but rather enveloping her in a large, inter-species hug, a gesture of care.

Hartshorn and Waerea echo Woolf’s usage of the sky as an image of what the recumbent perspective affords when it comes to attention and observation. In ‘On Being Ill’, Woolf satirises a certain type of ‘economic’ thinking through a voice that recurs to problematise the arguments made about the value of the frivolous and beautiful. This is the voice that calls the ill ‘irresponsible’ and ‘outlaws’ and describes illness as a state ‘with the police off duty’.[79] That this voice is satirical is clear from the passage which follows the argument that the ill person is able to access a new, more authentic perspective as a ‘deserter’ from the ‘army of the upright’. The narrator continues the passage with the view of the sky, which the ill

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[78] Waerea and Hartshorn.

[79] Woolf, p. 37; Woolf, p. 42; Woolf, p. 41.

person is attentive to for the first time in years, with the same movement from delight to critique:

> this incessant ringing up and down of curtains of light and shade, this interminable experiment with gold shafts and blue shadows, with veiling the sun and unveiling it, with making rock ramparts and wafting them away—this endless activity, with the waste of Heaven knows how many million horse power of energy, has been left to work its will year in year out. The fact seems to call for comment and indeed for censure. Some one should write to *The Times* about it. Use should be made of it. One should not let this gigantic cinema play perpetually to an empty house.[80]

The comment that someone should complain to *The Times* invokes a particular personality reminiscent of Woolf's character of the conservative Hugh Whitbread of *Mrs Dalloway* (1925) whose only real ability is writing bombastic letters to *The Times* about issues from dirty parks to the plight of the owls in Norfolk.[81] The narrator satirises a way of seeing that understands everything through its use, resources, and ability to turn a profit, while at the same time letting this voice inadvertently stumble on the core argument: that natural beauty does deserve an audience. The forward gaze of the marching army has resulted in the failure to notice much that is important and beautiful in the world, and the perspective of illness provides an opportunity to right this.

In Hartshorn and Waerea's 'Bed Rest I', the narrator also observes the play of the light and shadows over the course of a day, specifically through the refraction of the sun on to a wall at the foot of her bed. 'The shapes vary in opacity and / hardness, the harshest becoming the subtlest / seamlessly', with the narrator waiting for and cherishing the 'most / beautiful arrangement' when it occurs once a day.[82] The narrator moves with this circular time, ending up not inside a clock face but beyond it, when she looks for her favourite arrangement of light shapes: 'I am a

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[80] Woolf, p. 37.
[81] Woolf, p. 37.
[82] Waerea and Hartshorn.

small line around the edge of / a clock face watching an arm swing by when it / happens. It exists fleetingly, and then it is over'.[83] This type of expansive attention to beauty and the movement of time is fully detached from the clock as device of capitalist timekeeping. Close observation and enjoyment of the slow, unproductive movement allows the narrator to move outside the dial, encompassing time rather than trying to keep up with it.

Many short-form pieces of illness writing similarly employ imagery from the natural world to describe being in bed and the perspective it affords. Taking the example of the second issue of the magazine *Bed Zine*, which publishes the work of ill and disabled writers and artists, Miriam Sokolowska describes her bed as a 'bear's lair'.[84] Kelly Reid writes that in chronic illness, her 'bed itself was a landscape. It moved like the ocean, pulling up waves that could smother me one day, and provide sanctuary from the world the next'.[85] Sarah Kaplan Gould's poem 'Google wants to know your location' elaborates these metaphors, bringing them back to the act of noticing:

Bed is not   a desirable destination
you cannot   meet anyone there
cannot   tag yourself
cannot   enter the
                                   Hierarchy of Fun a.k.a.
                                   et al a.k.a. the
                                   Economy of Intimacy […]
but guess what   the internet is an isthmus;
we dangle
          and crave
we make everything
magnificent and slow
with our holy noticing;
how the sycamore
slicks green in the rain
and the muted light
spills crooked
across the dust

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[83] Waerea and Hartshorn.
[84] Miriam Sokolowska, 'Barłóg', *Bed Zine*, 2021.
[85] Kelly Reid, 'The Storm', *Bed Zine*, 2021.

on the dresser
how pristine, this
frozen waffle this
smudged mosaic
of a window this
chronic landscape
of creased sheets,
the hills and hills and hills
of your knees.[86]

The poem describes the sick bed as an undesirable location, not identifiable in the 'Economy of Intimacy' of Google and other social media's 'tagging' functions, which are used to signal the physical proximity with others. However, the narrator reconceives the Internet, and by extension the sick bed, through the imagery of an original type of mapping, as an 'isthmus', a piece of land connecting two islands. No man is an island with the Internet, Gould's speaker suggests, and emphasises the importance of digital communities for people with chronic illness. However, the opportunities facilitated by the Internet have a counterpart in a certain way of being. The sick person is equally sustained by the 'holy noticing' that makes 'everything / magnificent and slow'. The speaker brings the focus back to the bed and the perspective it affords: trees outside, light spilling in across the dresser. At the end, the bed becomes a 'chronic landscape', before the poem ends by zooming in on the sick person's body, whose knees alone have 'hills and hills and hills'.

In 'On Being Ill', Woolf's narrator complains that most literature 'does its best to maintain that its concern is with the mind; that the body is a sheet of plain glass through which the soul looks straight and clear'.[87] In reality, Woolf's narrator argues, 'the very opposite is true. […] The creature within can only gaze through the pane—smudged or rosy'.[88] Gould's speaker takes up the same metaphor, echoing

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[86] Sarah Kaplan Gould, 'Google Wants to Know Your Location', *Bed Zine*, 2021.
[87] Woolf, p. 32.
[88] Woolf, pp. 32–33.

Woolf's passage in her description of the 'smudged mosaic / of a window'. The objects Gould's speaker observes from her sick bed are all mediated so that they are not straightforwardly accessible: the sycamore is wet from rain, the light 'muted', the dresser topped with a layer of dust, the waffle 'frozen', and the window dirty. Something intervenes between the speaker and these objects, whether it is water, dirt, or frost. However, for the speaker, seeing the objects through the mediation of something else imbues them with additional aesthetic value as indicated by the description of the objects as 'pristine' even when dirty and creased. The ordinarily undesirable states in which the objects are found have their own kind of value as seen by the chronically ill speaker. The smudged window becomes a 'mosaic', a parallel to how the ordinarily 'undesirable destination[s]' of chronic illness and the sick bed afford alternative ways of seeing and being.

Contemporary feminist illness writers thus build on key interests in stillness, slowness, and attention to nature. The volume of examples from different texts, spanning genres, cultural contexts, and historical period in this section is intended to show that this is a common preoccupation of literary and feminist illness writing, which can be traced from the earliest canonical texts of the field to recent, more experimental examples. I argue that the attention to the natural world preserves the connection between post-work thinking and the examples of the flowers which 'toil not', and the parallel first described by Woolf to the ill, recumbent perspective. In the next section, I will look at the links between the more sustainable ways of working charted by contemporary feminist illness texts and the literary forms which they engender.

Collective thinking

A recurrent motif in this thesis has been the ways in which feminist illness writers reject a teleological narrative structure. This is the pressure, as Boyer describes, to tell the story of illness as ‘a story of “surviving” via neoliberal self-management—the narrative is of the atomized individual done right’.[89] Through this model, the ill person processes their experiences through storytelling with the purpose of restoring the sense of a coherent and agentive self.[90] However, in addition to the ways which have been analysed so far in this thesis—how writers use the framework of ‘work’ to emphasise the structural rather than individual aspects of illness, use forms like the list to break chains of causality, and centre accessibility work and impact into institutions rather than individual self-development as outcomes of the literary texts—this section looks at a final example of how contemporary feminist illness writers critique this narrative. I argue that they do so by privileging textual forms which can encompass different voices, different selves, and different states, doing away with the idealisation of a ‘coherent’, sane self in illness writing. I further argue that this contributes to post-work efforts to imagine alternatives to the current conceptualisations of the ideal neoliberal worker as self-contained individual and entrepreneurial unit.

The agentive, coherent, and ‘sane’ self is a model which excludes many people, not least those living with mental illness. Hedva describes this in the essay ‘In Defense of De-Persons’ (2016) published soon after ‘Sick Woman Theory’. In this essay, Hedva juxtaposes different pieces of text written in different mental and physical states. Incorporating fragments written while dissociating, for example, is

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[89] Boyer, *The Undying*, p. 9.
[90] Hyvarinen and others.

intended to remove a hierarchy between the authority of a 'healthy' and an 'ill' voice. Hedva instead makes a case for 'bad thinking' and 'messiness' as a way of not just rejecting the capitalist and neoliberal idealisation of the individual, but of affirming and envisioning the 'de-governable, de-master-able, de-possessed, de-owned, de-owing, de-private, de-privileged, de-individual'.[91] As discussed in Chapter 1, the 'coherent' self which is often promoted as the result of writing a traditional illness memoir overlaps with ideals of the eminently governable neoliberal subject. Incoherency found in illness resists this ideal, disturbing normative ideals of work ability and capacity.[92] This is significant, Hedva argues, because 'self-possession and self-mastery are the most legible and preferred forms of selfhood within a society built upon the ideology of possession'.[93] By instead giving voice and space to multiple selves, Hedva writes that 'a defence of a de-person could be said to be an embodiment of incompleteness, a demonstration of bad thinking, a performance of un-comprehension, a refusal of mastery at all'.[94] A lack of the 'self-possessed' voice typically found in memoir and life-writing can be a statement and be used to model less possessive and self-contained ways of being.

Theorists such as Mel Y. Chen argue that elevating slow and partial knowledge could help rethink intellectual labour, conceptualising these ways of knowing as 'cripistemologies'. Instead of presupposing (or idealising) a coherent, rounded, logical, and neurotypical 'thinker,' Chen argues that finding use for the partial could lead the way into more collaborative understandings of knowledge production makes clear that knowledge is socially developed and sustained.[95] A

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[91] Hedva, 'In Defense of De-Persons'.

[92] Hedva, 'In Defense of De-Persons'.

[93] Hedva, 'In Defense of De-Persons'.

[94] Hedva, 'In Defense of De-Persons'.

[95] Mel Y. Chen, 'Brain Fog: The Race for Cripistemology', *Journal of Literary & Cultural Disability Studies*, 8.2 (2014), 171–84.

similar intention is at the basis of contemporary feminist illness writing, as is clear from Boyer's description of the 'collective project of writing the sick, feminized body under current circumstances'.[96] For Boyer, illness writing is defined by its inherent failure, and thus comes to embody what it means to live under neoliberal capitalism: the body always in a state of lack in relation to ideals of health, personal growth, and productivity. Illness writing, because it must embrace some amount of failure, has a role in resisting these norms:

> The experience of illness can help us gain in courage even if we fail in capacity […]—but our failure is part of the collective project. […] We brave clumsy writing or speaking, that even in a crude form, a necessary idea will emerge as material for others to refine. When we are silent, we learn it makes room for others to speak. It's not just our *errors* we become brave about, but our projects'—and our own—*incompleteness.*[97]

Embracing the 'incomplete' and 'unfinished' as a default can also be seen in the commitment to publish texts without endings, as seen in the work of Alice Hattrick, Porochista Khakpour, and Meghan O'Rourke. 'Clumsy,' 'crude' writing—even the texts that were never written because of illness—are subversive because they are written from a point of view of vulnerability and interdependency rather than its individuality and perfectibility.

Lazard also emphasises that being silent can be a way of allowing space for others, and describes their work with the chronically ill and disabled artists collective *Canaries* as using this ethos to inform a new way of working together:

> As a group of chronically ill people, each of us was moving through these cycles of wellness and unwellness, which meant we weren't always able to work. Oftentimes, when one person didn't feel well enough to work, another person would be able to. It was about maintaining this hydraulic system of labour that comes from

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[96] Boyer, 'Tender Theory'.
[97] Boyer, 'Tender Theory'.

> collectivity. If there were multiple people working on a project, then it could happen. If we weren't feeling well, we didn't work. If we felt well, we worked.[98]

Lazard says that it feels strange to be 'individuated' when their 'work comes out of a long lineage of Black, disabled and queer people making art'.[99] And it is not only artistic inspiration that is traded, but 'ways of working' which are constantly 'being tossed back and forth'.[100] Rather than simply giving expression to the pain or sense of incomprehension in illness, contemporary writers are collaborating, experimenting, and inventing alternate temporalities and socialities. These in turn explore alternative ways of thinking and train people in thinking outside normative structures.

Looking at the texts in this way unites different observations made in this thesis. The 'collective thinking' of contemporary feminist illness writing can be found in the extensive use of citation and bibliographies. Similarly, magazines like *Bed Zine* allow authors and artists who have only written short pieces a platform for publication. The editor of *Bed Zine*, Tash King, describes that the magazine needs the collective force of all the different voices and perspectives to 'unpac[k] a complicated and fluctuating space'.[101] These publishing models emphasise that illness writing is a collective project. Each writer is a node in a network, contributing ideas and building on others, just as Keynes, Russell, and Woolf can be seen as belonging to a network developing ideas about the future of work in the 1920s and '30s.

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[98] Carolyn Lazard and Edna Bonhomme, 'Carolyn Lazard on Illness, Intimacy and the Aesthetics of Access', *Frieze*, 28 February 2022 <https://www.frieze.com/article/carolyn-lazard-edna-bonhomme-interview-2022> [accessed 9 January 2023].

[99] Lazard and Bonhomme.

[100] Lazard and Bonhomme.

[101] Tash King, 'Foreword', *Bed Zine*, 2021.

Moreover, juxtaposing authorial selves determined by different mental and physical states is a way of destabilising the ideal of a coherent narrative voice and allowing even severe decapacitation to have epistemological value and literary significance. Hedva does this in 'In Defense of De-Persons', and Abi Palmer similarly describes preserving different voices by using diary extracts and transcriptions of audio recordings alongside surreal and fictional passages in *Sanatorium* (2020). The same strategy also has a parallel in the juxtaposition of recollections, metatextual commentary, and descriptions of the situation of writing as described in Chapter 1, as well as in the inclusion of notes (Hattrick), diary extracts (Mantel), and e-mails (Hedva, Hartshorn and Waerea).

Collective thinking can also take the form of collective authorship. In the 'Correspondence' section of *In the Sick Hour,* Waerea describes how collective authorship also points away from the 'cohesive' selves which are idealised for their ease of expression and predictability, qualities that make a good worker. She describes experiencing 'multiple selves' within her illness, with pain flare ups and hormonal changes changing her voice and 'consciousness'.[102] 'It is easy to dismiss these things as deviations from my "self",' she writes,

> But at the end of the day, my relationships and life continue to be shaped by my interactions and decisions made in these various states. All these ways of being produce knowledge, reveal the textures of the systems at play around me. In this way, illness is epistemological.[103]

This emphasises how giving space to multiple selves, without prioritising one over the other, can form the entry to more capacious ways of thinking authorship.

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[102] Waerea and Hartshorn.

[103] Waerea and Hartshorn.

The fact that *In the Sick Hour* is collaboratively written challenges normative ideas of the single author which still dominate in literary writing and the humanities. Unlike the e-mails, which are signed off by one of the two writers, the poems are not ascribed individual authorship. The two parts of the pamphlet together chart a balance between metatextual commentary, which provides the site of situated knowledges, and the poetical experiments with collaborative authorship. The text therefore demonstrates close attention and commitment to a feminist epistemological way of illness writing. The writers' approach relies on the collision between the form of the poems, illustrations, and the e-mails. This juxtaposition insists on the importance of the illness text as *literary work* with a stress on both words.

The authors further distributed authorial agency by sending readers a page of writing exercises and prompts along with the purchase of the pamphlet. If followed, these prompts result in poems similar in structure to those included in the pamphlet. This again folds the production of the text into the publication, making it clear to readers how it was made and supporting them in writing their own anti-linear and nature-inspired poems. We can also see this as a gesture which metaphorically reclaims the processes and the 'means of production', positioning them as a resource shared between authors and reader. The emphasis on play and creative prompts also echoes post-work thinkers like Marcuse's definitions of meaningful work as that which integrates 'creative experimentation with the productive forces'.[104] Waerea and Hartshorn write their poetry on their own terms and invite others into the process and style. As the e-mails describe, they do so as a respite from the oppressive demands of workplaces and academia which they continually feel like they are failing in relation to.

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[104] Marcuse.

Another example of how writers on illness and debility have included types of collective authorship, even in an officially single-authored text, is Leslie Jamison's essay 'The Grand Unified Theory of Female Pain' which consists of a series of 12 interlinked vignettes on wounds, interspersed with 'interludes'.[105] The essay surveys different responses to women's pain, historical and current, through a wide range of sources, personal stories, and responses to the theme which have been 'crowdsourced' among Jamison's network. Spanning from literary women wounded by love, from Dickens' Miss Havisham to Tolstoy's Anna Karenina to the way dying women have served as plot mechanisms in *La Bohème*, the narrator emphasises the quality of 'woundedness' as a collective feminist cultural heritage.

Privileging networks over individuals is also emphasised in Chen's work on cripistemologies. As Chen cautions, 'a cripistemology needs to weigh questions of value carefully, well beyond a sheer reversal of negativity that can accompany some neoliberalized, otherwise highly capacitated identities of disability'.[106] According to this measure, texts that include different voices and texts written in multiple states of mind are more effective than ones which elevate one, particular state. This is because they remove hierarchies rather than reversing them, as, for example, Hedva's 'Sick Woman Theory' does. In 'Why It's Taking So Long' (2022) Hedva uses this argument to explain why they think 'In Defense of De-Persons' is the better of the two texts. However, they also observe that it makes it the more challenging text, something they argue has most likely decreased its popular appeal.[107]

These literary approaches encompassing different selves within a text propose that knowledge created from an ill point of view can stand in for the fact

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[105] Leslie Jamison, 'Grand Unified Theory of Female Pain', in *The Empathy Exams* (Minneapolis: Graywolf Press, 2014), pp. 185–218.
[106] 'Brain Fog', p. 176.
[107] Hedva, 'Why It's Taking So Long'.

that all knowledge is limited not only by standpoint, but also by differing abilities and capacities. I argue that these literary and authorial approaches centre debility in ways that position it as an important knowledge source for new ways of thinking interdependency and access. The final section elaborates why I see this as a key contribution of illness writing to post-work theory.

Dreaming from the sickbed

The recent resurgence in post-work thinking initially glanced over illness, seeing it as one more issue that could largely be solved by universal free healthcare and advances in technology. In the post-work manifesto *Fully Automated Luxury Communism* (2019), for example, Aaron Bastani argues that 'illness' is something that we have 'for the most part' already 'put[…] behind us'.[108] He acknowledges that while infectious diseases now no longer pose the danger they once did, the current increase in chronic and age-related illnesses could pose a massive burden on the healthcare system if current trends continue. More people with chronic and age-related illnesses like Alzheimer's require more (care, administrative, patient, medical) work, rather than less. His solution to this challenge is gene sequencing and gene therapies. As Bastani writes:

> while gene sequencing will change the provision of healthcare— creating preventative medicine that permits us to respond to illness before we even exhibit symptoms— the biggest breakthrough in biotechnology will be gene therapies. In terms of the leading causes of death, whose primary risk factor is age, this will create abundance in healthcare which even exceeds the exponential challenges posed by societal ageing.[109]

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[108] Aaron Bastani, *Fully Automated Luxury Communism: A Manifesto* (London; New York: Verso Books, 2019), p. 10.

[109] Bastani, p. 149.

He argues that even within the next 30 years, gene editing technologies like CRISPR could, ‘eliminate thousands of genetic disorders. Forever’.[110] Bastani sees illness and disability as problems to be solved and conditions to be eradicated. Acknowledging that illness and disability necessitates work from healthcare staff, care networks, and others, his solution is to make it disappear.

Illness, disability, and ageing have historically caused problems for utopian visions, as Piepzna-Samarasinha also observes in the passage quoted in the introduction to this chapter. According to the Bible, there is no illness in heaven: ‘No one living in Zion will say, “I am ill”’.[111] Robert Kastenbaum observes how illness and death are often glanced over in utopian thinking, with mentions centring on warfare or euthanasia.[112] In Sir Thomas More’s *Utopia* (1516), any person suffering from ‘a torturing and lingering pain, so that there is no hope either of recovery or ease’ is asked by officials and priests to starve themselves to death or, if it is available, take opium.[113] The presence of illness traditionally cuts right to the heart of a central problem in utopian thought. Writing about Aldous Huxley’s *Island*, in which cancer brings about the fall of the utopian state of Pala, Jerome Meckier observes that ‘in addition to functioning as an actual disease in *Island*, cancer also becomes Huxley’s metaphor for an ineradicable sickness in temporal man and his world, a sickness too essential an element of life for any society, no matter how perfect, to withstand indefinitely’.[114] In these utopias, illness thus expresses the

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[110] Bastani, p. 152.

[111] Isaiah 33:24, Bible, New International Version.

[112] Robert Kastenbaum, ‘Is Death Better in Utopia?’, *Illness, Crisis & Loss*, 13.1 (2005), 31–48 (p. 39).

[113] Thomas More, *Utopia* (London: Cassell & Company Editions, 1901), p. 96.

[114] Meckier, ‘Cancer in Utopia: Positive and Negative Elements in Huxley’s Island’, *The Dalhousie Review*, 54.4 (1974), 619–33 (p. 625).

essential fallibility of humanity and a nagging fear related to the question of how a human society can be perfect when humans are not.

Recent illness writing and work on care have taken a very different route. The texts analysed in this thesis seek to define vulnerability and interdependence as the default human (and ecological) state. As Taylor's keynote also emphasises:

> To state that we are living in an age of disability is not said with pride, but it is said with recognition that there are ways to transform, to find solutions, to centre care and interdependency and expansive visions of access. To create the conditions over the coming decades to learn from what disabled activists call 'crip brilliance'.[115]

Impairment, human or ecological, is a fact of life. Since this is so, there is much to be gained from paying attention to those who have knowledge of what it means to live well with impairment. Some of the most succinct descriptions of why giving space to illness—representing it, writing about it, exploring the knowledge it produces—are to be found in illness and disability writing. A key aspect, I argue, is how these texts think about the knowledge they produce, shaped by messiness, incoherence, and collaboration as described above.

Other recent manifestos have also emphasised the important of thinking *with* illness when discussing the future of work. The Care Collective's *The Care Manifesto* and Beatrice Adler-Bolton and Artie Vierkant's *Health Communism* (2022) place illness and health as key concerns and standpoints for constructing a future society oriented away from work.[116] From Marx onwards, post-work theory has idealised pre-industrial and 'pre-technological' work as the highest expression of human nature. In pointing away from this conception of the craftsman as the most idealised and authentic worker, illness writing thus challenges certain mainstays of post-work thinking even as it draws on other aspects, as demonstrated in the first

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[115] *Keynote Lecture by Sunaura Taylor*, loc. 46:18.

[116] Collective and others; Adler-Bolton and Vierkant.

section of this chapter. Conceptualising the ill woman as a worker fundamentally challenges the term, both according to Marxist and neoliberal conceptions. It therefore further challenges the efforts to rethink the future of work and emphasises the need for utopian post-work thinking in which human value is understood without recourse to production and work.

Having a serious and debilitating chronic illness means living in an extreme state of conflict with the ideals of the productive, neoliberal worker. However, Woolf's examples of colds and flu in 'On Being Ill' emphasise that even those who do not live with chronic illness regularly come into conflict with the cultural and societal demands of productivity. Under the banner of 'crip futurities', thinkers and writers have imagined utopian futures where illness and disability are centred. As Piepzna-Samarasinha writes, 'ableism warps and lessens everyone's experience of the world, from shame about asking for help to ideas of intelligence, worth, and who has the right to have a family'.[117] Redefining these ideals so that illness and disability are not failures, but simply other ways of being, can help expand notions of responsible citizenship to include more people. As Piepzna-Samarasinha describes, the objective is for chronically ill, Mad, and disabled bodyminds to be 'accepted without question as part of a vast spectrum of human and animal ways of existing' and for crip 'cultures, knowledge, and communities to shape the world' alongside other marginalised forms of knowledge.[118]

Is there a purpose to these literary utopian dreams? Edward Granter summarises the central paradox for Marcuse and other post-work utopian thinkers as the fact that 'in order for a new sensibility to emerge, the current ideology of

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[117] Piepzna-Samarasinha, *The Future Is Disabled*, p. 27.
[118] Piepzna-Samarasinha, *The Future Is Disabled*, p. 22.

production, consumption and capitalist systematisation must be transcended, but in order for it to be transcended, a new sensibility must first emerge'.[119] We are arguably at a time when the sensibility is changing; illness writing is just one of many fields in which capitalist idealisation of production, consumption, and the worker-citizen are under attack. Within literature and the arts, most work now reckons in some way with sustainability and climate change. But attitudes to work are changing more broadly, with the rise of anti-work sentiment online, with e.g., 'quiet quitting' coined for workers who try to get away with the least amount of work possible, refusing to go above and beyond for employers. On the largest forum on the internet, Reddit, 'r/antiwork' and 'r/workreform' have become some of the most popular 'subreddits', home to stories of terrible employers and workers' resignations, acts of rebellion, and discussions of how work could be different and better. On TikTok and Twitter, the sentence 'I have no dream job, I do not dream of labor' has become a popular meme. Commentators have observed a tendency in unionising, higher requirements for pay, and a wave of voluntary resignations in the wake of the Covid-19 pandemic, describing this with terms like 'the great resignation' or 'the big quit'.[120] As one puzzle piece among others, ill and disabled utopian visions contribute to these new sensibilities, offering the important perspectives of people who have traditionally been excluded from these visions.

David Graeber, in his thesis on the prevalence of 'bullshit jobs', argues that work in the way that it is currently mandated functions to keep people occupied;

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[119] Granter, p. 210.

[120] 'Transcript: The Great Resignation with Molly M. Anderson, Anthony C. Klotz, PhD & Elaine Welteroth', *Washington Post*, 24 September 2021 <https://www.washingtonpost.com/washington-post-live/2021/09/24/transcript-great-resignation-with-molly-m-anderson-anthony-c-klotz-phd-elaine-welteroth/> [accessed 8 February 2023]; Jacob Rosenberg, 'Workers Got Fed up. Bosses Got Scared. This Is How the Big Quit Happened.', *Mother Jones* <https://www.motherjones.com/politics/2022/01/record-quits-great-resignation-labor-workers-pandemic/> [accessed 8 February 2023].

people who are working to full capacity do not have time to dream or organise.[121] In texts by Woolf, Hedva, and Boyer, illness breaks this spell, providing new perspectives and dissolving supposed limitations. Boyer crystallizes this in *The Undying* when she represents the imaginaries of the sickbed as deriving power from an inability to recall rules and limitations:

> the deeply ill person in pain, in order to escape it, can sprint away from the pain-husk of the failing body and think themselves into a range beyond range. When pain is so vast, it makes it hard to remember history or miles per hour, which should make the sickbed the incubator for almost all genius and nearly most revolution.[122]

This recalls H. P. Segal, who argues that ‘to be effective as social criticism, a utopian vision should be concrete enough to be applicable to the real world; and it should be detached enough to be truly critical.[123] Illness and pain can unhinge a person from practical restraints in a way that can afford new thoughts and imaginaries. As Alice Wong, founder of the *Disability Visibility Project*, has written on Twitter: ‘Crip bodies were built for space travel. Crip minds already push the outer limits. We already master usage of breathing apparatuses and can handle challenging situations’.[124]

It is apt that Boyer names the specific topicality of the sick bed as a place for wild imaginations and political change. I have argued that ill and disabled writers continue to position the *work of dreaming* as a specialised form of labour to those who are recumbent and unable to work in the traditional sense of the word. As Piepzna-Samarasinha writes,

> we, disabled people, we dream a lot. In psych wards, of dead friends, of getting out of our parents’ basement apartment, on day 645 of pandemic not-leaving-the-house,

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[121] Graeber.

[122] Boyer, *The Undying*, p. 99.

[123] Howard P. Segal, *Technological Utopianism in American Society.* (Chicago: University of Chicago Press, 1985), p. 157.

[124] Alice Wong (@Sfdirewolf), Twitter, August 13, 2016, <https://twitter.com/SFdirewolf/status/764371929910218752> [accessed 20/05/2023]/

> of lovers who will be sweet to us in autistic, Deaf, disabled ways. We haven't stopped dreaming all through Trump and the pandemic. We go to bed every night dreaming of the disability justice future. And we will keep dreaming these wild disability justice dreams, every night and day, until we meet her. We are meeting her right now.[125]

This chapter has marked a return to the sick bed as a site with special significance for those who are chronically ill and who spend much of their time there. Chapter 1 showed the sick bed as a place of creative and activist work. Through analysis of passages in Woolf, Hartshorn and Waerea, and the texts in *Bed Zine 2*, this chapter has returned to the sick bed as an active space—but a space for utopian thought and leisure rather than work in the traditional sense.

Those who have only read Hedva's 'Sick Woman Theory' may think that contemporary feminist illness writing advocates for the abolition of work. However, rather than imagining a world without work, I have argued that most contemporary feminist illness texts reimagine what work could be and its role in future societies. They do so by asserting the importance of creative work made from an ill perspective (Chapter 1). They expand the definition of work to the efforts and labour entailed by illness, making way for the confines and conceptualisations of illness to be negotiated collectively. By pointing out the similarities to precarious work, they imagine the ill person as part of a unionised and revolutionary movement of workers, ready to overthrow the capitalist and ableist foundations of current hierarchies (Chapter 2). And by intervening into workplaces, and/or re-imagining the process of authorship, writers model new and more inclusive sites of work (Chapters 4 and 5). They see work not as valuable in itself but as a means to care and access. I therefore argue that we should recognise the contribution and important corrective offered by contemporary feminist illness writers to utopian post-work thinking.

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[125] Piepzna-Samarasinha, *The Future Is Disabled*, p. 45.

Conclusion: returning to the 'poet-economist' of illness

I started this thesis with Boyer's narrator in 'Woman Sitting at the Machine' and her wish for an 'alien […] poet-economist' to explain how cancer is work and pain creates profit.[1] More than anything else, the narrator wishes that *she* could take up this role. 'I could have been the poet-economist from an alien earth,' she writes, 'if it wasn't for the fact that I can't remember, can't visualize, can't focus, can't recall words because I'm on this earth'.[2] Chronic cognitive impairment after cancer treatment makes objective analysis impossible, she writes. 'I'm thinking but not thinking very clearly,' the narrator states,

> can't tell if a profitable illness is a type of work or a type of commodity or some other economic classification. I look for the proper economic term for a body as a sinkhole as a war wound as a poisoned animal as the saddest, most cut-open thing to ever exist.[3]

The perspective from the midst of illness is limited and unfocused. 'This earth' is a place in which both work and illness are shaped through the forces of capitalism, almost unthinkable as experiences separate from the creation of profit. And yet neither illness nor work quite fit economic classification. The potential metaphors multiply, negate, and compound each other.

The narrator of Boyer's *The Undying* takes something different from the limitations of the ill perspective. When she claims that the sick bed is 'the incubator for almost all genius and nearly most revolution,' it is because the limitations of illness are also its strengths and the reasons why the ill perspective must be taken seriously.[4] Impairment and the inability to think 'clearly' afford a fresh view,

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[1] Boyer, *A Handbook of Disappointed Fate*, p. 172.
[2] Boyer, *A Handbook of Disappointed Fate*, p. 172.
[3] Boyer, *A Handbook of Disappointed Fate*, pp. 175–76.
[4] Boyer, *The Undying*, p. 99.

unfettered by the limitations of ordinary classification and norms. This allows her to see past the confines of normative ways of thinking and to dream new societies. On these alternative earths, illness may not even need an ‘economic classification’; abilities and capacities could be distinct from current hierarchies of economic and moral value.

I have argued that contemporary feminist illness writers develop an aesthetics of impairment which embraces the inability to ‘remember,’ ‘visualize,’ ‘focus,’ and think ‘objectively’. If we conceive of the human being as vulnerable, interdependent, and embedded, the literary forms and modes of production we use must reflect this. This includes writing collaboratively, thinking together, and recycling labour. Texts derive value from the ways they engage with others and participate in joint projects, which are never quite finished, but to which each work and writer can contribute ideas or complications. Writing from an ill point of view is thus not about overcoming illness but rather about exploiting its affordances and the knowledge that living with illness brings. Contemporary feminist illness writers remind us that despite capitalist idealisation of constant personal and economic growth, bodyminds and planets have limits.

The texts I have analysed in this thesis demonstrate how demanding and active the state of chronic illness is. Sara Ahmed describes privilege as ‘an energy-saving device’.[5] Marginalisation almost always comes with extra labour, much of which is invisible to those who do not need to undertake it. Chronic illness is a salient example of this. From the outside many chronic illnesses can look like they are defined by passivity and rest: the inability to do and take part. But chronic illness

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[5] Sara Ahmed, ‘Feeling Depleted?’, *Feministkilljoys*, 2013 <https://feministkilljoys.com/2013/11/17/feeling-depleted/> [accessed 14 May 2023].

also means a host of new activities and tasks; effort and time expended for daily maintenance, routine monitoring and treatment, and skilled navigation of complex systems and fields of knowledge. This is in addition to the ongoing process of negotiating the experience of constantly falling short of societal expectations.

I have contended that living with the daily realities of limitation makes the narrators of contemporary feminist illness writing able to think about labour, work, and leisure in significant and novel ways. Contemporary illness writers continually engage with concepts of work—creative work, the many types of labour entailed by illness, access work—and how these shape, and in turn are shaped by, illness. In doing so, they press at the boundaries of what the concept of work can contain. Johanna Hedva's 'Sick Woman Theory' and 'Why Its Taking So Long' are examples of essays written at either end of the period this thesis surveys. They each challenge the concept of work from opposite ends: one encourages the end of work as we currently know it, the other suggests escalating a particular type of labour, access work, until there is time for almost nothing else. Both propose that stressing the current structures through withdrawal or intensification of certain work will push the system to its breaking point, allowing for the building of new social infrastructures. In expanding the concept of work until it contains even its potential opposites—leisure, dreaming, rest, illness—contemporary illness writers exploit the political and moral valence work carries but also imagine worlds in which claiming an identity as a worker is not necessary for accessing political agency and moral value. They appropriate and reimagine work as a way of thinking about what is important in life.

The power of the poet-economist is not in making sense of everything but rather in making visible the ways the world currently does not make sense. This allows for new, necessarily imperfect utopian imaginings. The poet-economist of illness is a hybrid figure, uniting two figures that often seem opposed in contemporary US and UK society. Poetry may represent the uncertain, emotional, subjective, and frequently that which is oppositional to the status quo. Economics instead wields power as an epistemology which is allowed to govern the distribution of resources. The figure of the poet-economist pushes the two together to see what happens. As in Russell's vision for society, poetry and economics meet in leisure; uncoupled from notions of work, the two are united as active ways of thinking about value. The figure of the poet-economist refuses a binary between the arts and the social sciences, and affective and economical classifications, reminding us that value is not to be assumed but to be decided.

The texts analysed in this thesis suggest particular inroads into some of the most important questions of our time, questions that are animating thinkers from across the disciplines. In the mid-nineteenth and first half of the twentieth century, thinkers from Marx to Keynes started considering how the advances of technology could set humans free from work as toil and drudgery. However, production was accelerated in parallel to the pace of technological advances, and the profit gained through new technologies has not been shared. The need to work still shapes most people's lives. With the current advances in machine learning/artificial intelligence, however, the ability to automate work is exponentially increasing. This presents an urgent need to consider how we can distribute work, resources, and security more equitably and justly. Finite resources mean that the current rates of economic growth cannot continue. In presenting texts and lives in which growth is neither attainable nor desirable, contemporary feminist illness writers contribute to making these alternative ways of structuring society thinkable.

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