

## Review articles

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# Ill systems

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Review article: Alice Hattrick, *Ill Feelings*, Fitzcarraldo Editions 2021

The year 2023 is arguably not the best time to recommend a book about illness. More than three years after Covid-19 infections first made the headlines, many people are experiencing what the WHO has described as ‘pandemic fatigue’ - the feeling of having had enough of all the talk about illness.<sup>1</sup> Yet, at the same time, there may be no better moment to read Alice Hattrick’s *Ill Feelings*, in which the author describes their daily struggle with chronic fatigue syndrome (ME/CFS), and what it means to be clinically exhausted in a society that expects you to ‘function’ at all times - not least because the book speaks to and of people who have no choice but to deal with illness every day of their life, and for whom going back to ‘normal’ pre-Covid life is not an option.

As someone who has been struggling with Long Covid for the last three years, I cannot recommend Hattrick’s book enough to anyone who has to live with chronic illness (as well as to anyone who wants to learn about what that feels like). However, this book is also for everyone else, for it discusses an aspect of illness that has, amongst all the Covid talk of the last few years, received far too little attention - the fact that illness cannot be understood solely as an *individual* experience of ill health. Illness is a *social* phenomenon - for which we are collectively responsible. Well-researched, deeply engaging and wonderfully written, Hattrick’s book is a reckoning with what it means to be chronically ill in a society that is set up to work for ‘normal’ people only - and how things could be different.

Hattrick is, of course, not the first person to point to the social dimension of illness, but the book contributes to an existing body of literature, developed by

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queer and feminist writers in particular, who have long described the social life of illness. In *Illness as Metaphor*, Susan Sontag, for instance, famously wrote about the seemingly unbridgeable abyss between the 'kingdom of the well' and 'the kingdom of the sick'.<sup>2</sup> Virginia Woolf, in her landmark essay *Being Ill*, illustrated the difference between sick life and 'normal' life by comparing the ill person taking to their bed to a 'deserter', while the 'army of the upright marches to battle'.<sup>3</sup> And then there are women like Audre Lorde and Anne Boyer, who powerfully wrote about their reckoning with breast cancer.<sup>4</sup> Both writers refused to be stylised as either victims or heroines, and fought to encounter cancer and mastectomy on their own terms and with appropriate anger. The novelty of Hattrick's book is that it contributes to this longer-standing conversation through a particular focus on life with *chronic* illness, of which they present a collective account. In part, Hattrick's book is a collective portrait of these and other well-known women, queer people and 'crips' (drawing on Alison Kafer's queer feminist use of the term).<sup>5</sup> It narrates these and other people's experiences of illness alongside the author's own, in order to skilfully diagnose all the subtle ways in which chronic illness is constructed as a societal problem through social interactions. Hattrick shows us that illness is not a lonely fate but, rather, a collective endeavour: doctors, nurses, family members, friends and politicians all play a crucial part in shaping what it means to be chronically ill today.

To start with, Hattrick demonstrates how other people play a role in determining whether a person does in fact 'qualify' as a properly ill person - or whether one is just 'pretending' or 'exaggerating', using their illness as an excuse to be lazy. Hattrick shows how this applies in particular to patients who face illnesses 'without a reason - no biomarker or treatment or explanation', like those suffering from ME/CFS or Long Covid, who are frequently deemed, by society, 'as fakers, scroungers, lazy and privileged, and ... [as] less-than-human, deserving of fewer rights, less pay, and less security and care' (p17). Throughout their book, Hattrick unpicks and zooms into situations that illustrate how this process takes place through often innocent-sounding and even well-meaning comments. For instance, Hattrick cites a letter of 20 February 1922 in which Woolf wrote to Vanessa Bell about the visitors to her sickbed:

They come in and sit down and produce a bunch of violets, and then say how nice it is to be in bed, and how they wish they could be in bed, and how well I look - which as you know always makes me furious (quoted on pp156-157).

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Like Woolf and Hattrick, I also frequently experienced such subtle but upsetting remarks about how ‘nice’ it must be to be in bed all day. When I told other people that I had to go on partial sick leave because my symptoms made it impossible for me to work to my old capacity, they frequently responded that they’d ‘also like a holiday’, but that they couldn’t ‘afford’ one, apparently equating sick leave with (undeserved) time off. Even one of my doctors once told me I should ‘enjoy the time off work’. Such remarks were striking to me and problematic in a number of ways. I thought they illustrated how chronically overworked many of the people around me were. The fact that they were desiring sick leave to catch a breath was symptomatic of a system of work that didn’t seem healthy. Besides that, in my own experience, sick leave was far from ‘recharging’ in a way that a holiday might be - it was a question not of relaxation but of survival. Put differently, while the defining element of a holiday may be that you use your time in the way you *want to*, what you do during sick leave depends on what your body *allows you* to do. These kinds of remarks from doctors and colleagues ran completely counter to what I struggled with the most - in all the time I’ve been ill, I’ve wanted nothing more than to be able to work and do more, but I simply was not able to. Constantly having to hold yourself back, saying no to things you actually desperately want to do, feels terribly frustrating, like driving a car with the hand brake on.

Feeling (or rather being made to feel) guilty for being ill also derives from these being assumptions about how an ill person should behave and what they should *look like*. Woolf’s visitors’ remarks about *how well she looked* are a case in point. ‘What does a sick woman look like anyway?’, Hattrick asks (p117). This point particularly resonated with me, because ME/CFS and Long Covid patients often do not ‘look ill’ - illness and disability are not always visible. In the everyday life of chronically ill people, this can lead to a lot of complicated negotiations. For instance, I can usually manage a day in the office and, as Hattrick puts it, ‘pass as “normal”’ (p315). People who see me there probably think - and frequently tell me - that I look ‘much better’ or indeed ‘fine’. What they do not see, of course, is that if I go into the office one day, I will be (even more) incapacitated the next day - and the day after.

Throughout their book, Hattrick demonstrates how chronically ill people have to negotiate ill life on two fronts. On the individual front, it means being forced to assess and carefully ‘manage’ one’s limited amount of energy on any given day - deciding to do some things and not others. In my own case, for instance, if I had

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a meeting at work, I could not also call my mum in the evening. It was one or the other. On the social front, what makes this daily struggle of choosing where to put your energy even harder is that when you 'look fine', it's difficult for people to understand why you have to constantly cancel things. 'Sick life', Hattrick writes, is 'an internal experience that is measured and judged by others who say, "You look well"' (p61).

Ultimately, what Hattrick's book powerfully shows is that the social (and medical) construction of chronic illness is profoundly political. One key aspect of this is the deeply gendered nature of our understanding and experience of illness. One spectre which has haunted women in particular is the diagnosis of 'hysteria', as Hattrick and their mother, who also faces chronic illness, have experienced a number of times. Startled by this ('wasn't that a nineteenth century diagnosis?'), Hattrick shows how the reference to 'hysterical' feelings has been used to delegitimise women's experiences of their illnesses - and ways of life - throughout history. As well as this gendered dimension of illness, which runs through their book, Hattrick also highlights the power of medical actors to name illnesses and treatment, as well as to influence which care infrastructures governments choose to provide or cut. The book cites in evidence a medical conference that ultimately informed New Labour's 2006 Welfare Reform Bill. As Hattrick reminds us, New Labour's strategy was to halve the number of people claiming Incapacity Benefits - thus 'turning long-term sickness and chronic illness into a political issue' (p208). Hattrick discusses a medical report that informed the Bill, which they see as casting chronic illness and disability 'as a form of malingering', 'deception' or 'some kind of lifestyle choice', to be sanctioned, they argue, because this was 'unacceptable under neoliberal capitalism' (pp212, 213). In practice, this meant that families such as their own - 'a family of one disabled adult and two children' - had to live off around five thousand pounds a year (p213).

Hattrick's own story illustrates the several ills of the system in which we still live today. This is a system in which ill people are further marginalised by measures that are directly related to the inequalities from which they already suffer. Being ill, in other words, sucks even more when you are poor, precarious, or exposed to gendered or racialised violence.

What becomes clear when reading Hattrick's book is that we currently live in a system that punishes ill people further in various ways, whether it is because

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they are being disbelieved, through lack of appropriate care or through benefit sanctioning. Yet falling ill is, of course, something that can happen to anyone, at any time. We often deal with illness in society as something *exceptional*, something to lock away, look away from or move on from once it has passed - as in the case of the Covid pandemic - but sometimes illness does not pass. In fact, we could say that illness is the norm rather than the exception. As Sontag reminds us in *Illness as Metaphor*, even if we'd prefer not to, most of us will fall ill in one way or another at some point in our lives. Being ill, in other words, is not a question of 'if' but 'when'.

What we *can* choose, however, are our ways of dealing with illness. As Hatrick shows, current social responses frequently make the struggle with illness that much harder, and treat ill people as a nuisance or problem to be cured. Being ill is bad enough as it is. How we treat less able people, what we say to someone who is ill, how and how much we expect people (that is, *all* of us) to work, what kind of care is provided and who has access to it - these are all questions we do have a choice about. As Hatrick concludes, 'It is ableism, not pain and fatigue, that structures the disabled experience' (p300).

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### Notes

1. <https://apps.who.int/iris/bitstream/handle/10665/335820/WHO-EURO-2020-1160-40906-55390-eng.pdf>.
2. S. Sontag, *Illness as metaphor*, London, Penguin 2002, p3.
3. V. Woolf, *On being ill*, Ashfield, Paris Press 2012, pp12, 16.
4. A. Lorde, *The cancer journals*, San Francisco, Aunt Lute Books 1997; A. Boyer, *The undying*, New York, Farrar, Straus and Giroux 2019.
5. A. Kafer, *Feminist, queer, crip*, Bloomington, Indiana University Press 2013.