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Tom Lee – The Benefits of Chronic Illness

In my early twenties, along with an obsessive but largely un-acted-upon desire to become a writer, I was afflicted by an enduring physical malaise. It is hard now for me to separate these two dominant features of my life at that time, perhaps with good reason. I was always exhausted. I had a constant sore throat. I had headaches that went on for days. My mind was often foggy, dulled. I was checked for everything and I saw everyone—doctors, specialists, homeopaths, nutritionists, hypnotists, Reiki healers. When my acupuncturist felt she was making no progress she referred me to her mentor and he interviewed me about my symptoms in front of a lecture theater of trainees, who discussed the enigma of my case and took turns drawing my tongue. Eventually I was diagnosed with ME/chronic fatigue syndrome by a consultant, but this brought no hope of treatment except for a handful of sessions of cognitive behavioral therapy. I was struggling at work and when my temporary contract came to an end I left London and went to South America for six months, during which I felt no better. On my return home, anxious about the future and unsure how I would cope with the demands of a more orthodox job or career, I began a graduate course in creative writing. I hoped—but didn't really believe—that writing would save me.

The sickly writer is a staple, a cliché, of literary history, enduring and strangely compelling. Thomas De Quincey and the neuralgia, digestive issues, and visual problems he numbed with opium. Charlotte Brontë with her headaches, bodily pains, and hypochondria. Guy de Maupassant and Alphonse Daudet and syphilis. James Joyce and his failing eyes. Flannery O'Connor and lupus. And perhaps most notoriously, the consumptive writer—John Keats, Robert Walser, Katherine Mansfield, George Orwell, and many, many others. In some cases, illness, particularly mental illness, has become a key part of the writer's literary iconography, near impossible to disentangle from the work: Sylvia Plath, Virginia Woolf, Robert Lowell, David Foster Wallace. In many of these cases their sickness seems to have added to their authenticity as writers, that they were too cerebral or too sensitive for the demands of the world, that their suffering brought to their work depth and insight that were unavailable to others, the humdrum well.

Marcel Proust is the archetypal writer in this tradition. Troubled by chronic asthma since childhood, at the age of thirty-eight, in 1909, he

withdrew into the bedroom of his apartment on the boulevard Haussmann to work uninterrupted on *À la recherche du temps perdu*. He lay in bed in semidarkness, the windows closed and heavily draped, writing at night and sleeping during the day, waited on by servants schooled in the strict routine and habits he followed in order not to further upset the delicate balance of his health. The asthma, which had nearly killed him several times, had evolved into a more general sensitivity to the physical world. Smells, in particular, were regarded as a severe threat. Visitors were forbidden to bring flowers or wear perfume. Cloth handkerchiefs were used for one wipe of his nose then discarded. Likewise, towels were dabbed on his body once, and then a new one was needed. As he told his servant: “My dear Celeste, you don’t realize that if I use a towel twice it gets too damp and chaps my skin.” The walls of the room were lined with cork to protect his inflamed senses from the noises of the street.

It is not hard to make the link between Proust’s health and his creative work. *À la recherche* is, famously, a novel of heightened sensation, with pages devoted to the elucidation of a particular smell or noise. However, in his book *Tormented Hope: Nine Hypochondriac Lives*, Brian Dillon makes the case that Proust’s health played a more subtle role in the facilitation of his creative work. At that time, asthma was regarded as a nervous illness and Proust was attracted to the idea that this was a necessary element of the artistic persona. In *À la recherche*, Dr. du Boulbon claims, “Everything we think of as great has come to us from neurotics. It is they and they alone who found religions and create great works of art.” From his childhood onward, Proust’s frailty had led to him being spoiled, indulged, and protected. As he grew older, these habits became a structure through which he could legitimize his desire to withdraw from the world and give himself only to his work. The compulsions of creativity and of illness become inseparable. As Dillon says, “At once crippled and cosseted by fear, the hypochondriac suffered in order to work, to write or to discover in solitude.”

When I began writing and being ill, I, too, submitted to a kind of Proustian regime. I took long, groggy naps in the afternoons and frequent, morose walks around the park. In the evenings, I took boiling hot, energy-sapping baths. I went to endless appointments, took homeopathic remedies and nutritional supplements, began diets that cut out one thing or another, stopped drinking alcohol and caffeine entirely. I tried yoga, Pilates, and the Alexander Technique. And in between all this—which, after all, was

not much—I wrote. I wrote seriously, with a joyless determination that reflected my sense that most other options for life and work were now closed to me.

It is too much—too pseudo-psychological and self-serving—to say that I manufactured my illness in order to become a writer. At the time I certainly felt the opposite was true, that being unwell was a hindrance to the writer I might become. With hindsight, however, it is also possible to see how I was helped. Like Proust’s asthma, ME/CFS has long been associated with languid malingering, typical of the privileged, the educated and leisured class who could afford to be ill. Regardless of its precise pathology or psychopathology—and I certainly rejected any mental aspect to it at the time—the range of symptoms, the lack of a straightforward diagnostic test or single effective treatment, the cycle of good and bad periods, its disputed nature, all make it curiously adaptive to the sufferer’s own psychological maneuvers. Dillon quotes Proust’s biographer Ronald Hayman: “It becomes hard to locate the hairline crack between the unavoidable and the theatrical.”

Writers, or at least those who want to be writers, are natural self-dramatizers. They are looking for reasons to write, and they require a sufficient sense of entitlement, a creation myth. William Burroughs claimed that one of his experiments with the cut-up method revealed that it had been necessary for him to accidentally shoot and kill his wife Joan Vollmer in order for him to become a writer—a retrospective self-justification that was of no use to Joan. Many writers have pointed to the death of a parent as a trigger for their career. The truth of these narratives is perhaps less important than the enabling role they play in writers’ minds. My illness gave me my own creation myth and helped me to take myself seriously as a writer. Over time I discovered that there were many other writers who had struggled with their health, that illness was almost a badge of honor. Whenever I came across one I feasted on the details and felt validated, consoled, hopeful.

Two-time Booker Prize winner Hilary Mantel was—in the classic writer mold—a sickly child. Christened “Little Miss Neverwell” by her family GP, she endured years of pain and misdiagnosis before correctly diagnosing herself with endometriosis. “Sometimes people try to persuade me that it’s made me a better writer in some way, or that it has meant that I could keep the world at bay,” she has said, dismissing the thought. But she

has also said, “If it hadn’t been for my poor health, would I have become a writer at all? Probably not.”

In 2012, I became seriously ill with pneumonia and sepsis and spent four weeks in an induced coma. This presented me with another opportunity. In the aftermath, unable to work for months and with no demands except that I should get well, I began to write my novel, *The Alarming Palsy of James Orr*. The novel centers on a man around my age who is struck down overnight by a mysterious affliction that gradually causes his life to unravel. I had published a collection of stories a few years before—the ones I had eked out while unwell in my twenties—but with the pressures and distractions of making a living and raising a family, a novel had always eluded me. Now I had the time and, it turned out, the material.

There is a strong danger of being complacent about these things, of turning real misery into the vehicle for a pretty story about becoming a writer, of inventing yet another convenient narrative. As Mantel has said bluntly, “Chronic illness has nothing to recommend it.” A friend of mine, a brilliant novelist, only began writing when a chronic and unidentified illness cut short a different career. He has a diagnosis now, after many years, but the treatment is limited. “It’s good experience for writing,” he says, “and it makes you see the world in a different way, but suffering never seemed to me to be worth the price of admission.” It depends, too, on there being the right amount of illness: enough to facilitate the work, not enough to get completely in the way. When my anxiety, the anxiety that I was probably incubating throughout my twenties, exploded into a comprehensive breakdown in my mid-thirties, I couldn’t write at all for two years. If the sepsis in 2012 had killed me, which it very nearly did, this evidently would not have done much good for my writing.

Mantel rejects her illness as a creative force but without it we would certainly not have the savage brilliance of her memoir, *Giving Up the Ghost*. As she says herself, we might not have had Mantel the writer at all. Ultimately, it is futile to try and separate the two. My novelist friend says, “I’d happily not suffer if it meant I never wrote another word,” but concedes that “even though you’d do anything to be rid of it, you do in some way become attached to your own affliction, as it’s a part of you, and your identity wraps up with it a little.” The writer Chloe Aridjis has said something similar about her experience of insomnia: “Our conditions define us, add contours, accents, drama to our lives. And the longer they

accompany us, the more years we spend together, the harder it is to part ways.” Asked, in the aftermath of her first Booker win, what she would have done if given the choice between literary success and good health, Mantel replied, “I think I’d choose the health.” And yet it is not a choice any of us get to make.

Tom Lee is the author of a novel, The Alarming Palsy of James Orr, published by Soho Press, and Greenfly, a collection of short stories. His essays and fiction have been published in Zoetrope, Granta, The Guardian, The Sunday Times and The Dublin Review, among others.