

The Unique and Their Dis-Eases

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“The opposition between the real and the ideal is an irreconcilable one, and the one can never become the other: if the ideal became the real, it would no longer be the ideal; and if the real became the ideal, there would only be the ideal, and the real wouldn’t be at all ... I am owner of my power, and I am so when I know myself as unique.” Max Stirner, *The Unique and Its Property*

In coming to write this, I am approaching this with a desire to articulate what wisdom and insights I have gleaned from particular experiences that I have undergone, pertaining most of all to the matters of illness and individuality. This will include the affirmation of those individuals who have also shared thoughts on the subject of health and illness, whose thoughts have been useful for me.

I was born with a pineal germinoma in my brain, which I became aware of on my 19th birthday after having had an MRI scan to investigate why my eyes had moved out of alignment and I was experiencing double vision. What followed from this was almost two years of regular reviews and treatment, with the tumour killed via radiation therapy in the Summer of 2012. Then in the November of 2023 I was diagnosed with an ocular tumour behind my left eye, which was surgically removed in the February of 2024, and I am still undergoing regular check ups regarding - with an MRI scan booked in for tomorrow morning and an ophthalmology appointment booked in for next week. Chronic-fatigue is something that I have been experiencing and dealing with during this latest health struggle, which is easing and lessening but at a pace slower than I would want, and I now have increased light sensitivity. With regards to the residual impact of the brain tumour, I live with dorsal midbrain syndrome and vertical gaze palsy, which means I have impaired upward gaze. That I am someone who self-describes as a pessimist and who lives with increased light sensitivity and a decreased ability to look up is a continuous source of amusement to me.

But here I have arguably reached two ideal, two ideas or “Realities” of how my body should be. This is to suggest that the idea of impaired upward gaze rests upon the ideal of correct upward gaze; to suggest that the idea of increased light sensitivity rests upon the ideal of correct light sensitivity. These ideals can both be expressed in naturalist accounts of health and illness, based in biology, and normative accounts of health and illness, based in social values and norms. It is true that these could be brushed off as ideals that are not real, but there is a realness to the experience of impaired upwards gaze and increased light sensitivity that I cannot really brush

off. This realness is the phenomenological encounter of impaired upwards gaze and increased light sensitivity; how it feels to experience both of these lasting and lifelong impacts upon my body and my being; how my sensual experience of being in the world is affected and changed. The phenomenological encounter is real to me, the sensation, the feeling, the experience.

The phenomenology of illness is something wonderfully affirmed by Havi Carel, someone who also lives with chronic and life-altering health struggles, in her book *Illness: The Cry of the Flesh*, which has been incredibly valuable to me during this current health struggle. In this book Carel affirms that chronic and life-altering illnesses can create metaphysical changes in the experience of being in the world. Suddenly the world has a different quality to it. Change has occurred. What was real no longer is and other realnesses are apparent. The easiness of climbing stairs is no longer real, while the difficulty in the act is. I remember after my second brain surgery it taking multiple attempts to stand from the toilet and how much my experience of being in the world was radically altered in that moment. Changes in my colour vision with the ocular tumour impacting on the area behind my eye, and the world felt less beautiful; my colour vision improving and the world being more beautiful again. These metaphysical changes in experience are radically individualising.

This is similar to Friedrich Nietzsche's affirmations of suffering and pain as a means of experiencing philosophical insight, which I most appreciate in his work *The Birth of Tragedy* - it is worth noting here that Nietzsche is also someone who lived with chronic and life-altering health struggles. Nietzsche's affirmation of *amor fati*, to love your fate or life in the context of painful struggles, encourages his readers to not embrace resentment and to say yes to life. In the year following brain tumour treatment and particularly while I was struggling with intense feelings of resentment, Nietzsche's writings were of intense value to me.

Now the singularly most intense pain I have ever experienced were the migraines I experienced with hydrocephalus brought on by the brain tumour blocking the flow of cerebral spinal fluid through my brain, creating intense pressure. My first brain surgery was an endoscopic third ventriculostomy to stop hydrocephalus from killing me and the placement of a ventricular reservoir in my brain; and the surgeon told me after surgery that he would have guessed that my chances of survival just before the surgery were less than 10% - there is a line in one of Camus' notebooks, written while he was writing *The Plague*, where he describes doctors as enemies of God for resisting death, which I love! Words will never really articulate that experience, in its sheer aw-fulness. The before unimaginable pain, where I felt like my head would be unable to contain what was agonising it, is something I would not wish on anyone. And I do not resent it, and consider it to be one of the most valuable experiences of my life. That pain affirmed two truths that to me are utterly real and intensely valuable. The first of these, in that no one else experienced the hydrocephalus migraines that I experienced, is the truth of my embodied individuality - which is not to deny that there were and are those who walked and now walk alongside me through my health struggles with love (which is amazing) and empathise and feel pained too, but to affirm that they are different and differentiated with embodiment. The differentiation of my body and embodied experience of pain from those who I was with amidst that experience was non-transcendable and inescapable, as it has been and is with other experiences of pain. The second truth that hydrocephalus rendered plain to my mind is that of my primal and instinctual desire for life. Pain renders plain to me my desire for life. In his essay *Existential Monday and the Sunday of History*, Benjamin Fondane wrote "(t)he sick person cries out for 'The possible!'", and, with possibility being life (and impossibility being death), this harmonises with my experience

of hydrocephalus intensely - my being cried out for the possibility of surviving, overcoming and out-living the brain tumour.

But possibility is not always desirable. The great philosopher of uncertainty, Lev Shestov, affirmed in his thought that all things are possible and tomorrow I will be having an MRI scan to see if there is a tumour growing behind my left eye again, which could possibly turn cancerous; and while it is unlikely that there will be a tumour there and that that would become cancerous, it is by no means impossible. I am at an increased risk of strokes, due to the radiation therapy to my head and my genetics, with my mother dying of a stroke at the age of 34 (which I will be reaching in 3 months) and my nan having a mini-stroke in her 70s, and, though I do all I can do to lessen the possibility of me having a stroke, it is not impossible that I will experience a stroke and that that could be my undoing. The possibility of my impossibility is real to me and while I agree with Shestov that all things are possible, I differentiate from him with the affirmation that all things being possible includes the possibility of impossibility.

At this point in writing I feel myself becoming somewhat distracted and looking to my book shelf. The other day I was flicking through my collection of Albert Libertad's writings - one of my favourites from the individualist-anarchist conversation - who I appreciate most for his writings on life as revolt, the joy of life and for the stories of his direct rebellions, which he lived whilst living a life with the impacts of life-altering illness. Now my eye moves to a Kafka collection, who lived with hypochondria and then died of tuberculosis, and then to a book by Fredy Perlman, who lived with heart damage following rheumatic fever at 10 years old. To think of the possibilities that their fleshed cried out for and the value of their creativity to my life and the lives of others who also find them inspiring, is incredible. This reminds me of Havi Carel sharing in the aforementioned book by her of philosophy being a therapeutic tool for her, amidst her health struggles. I know that I have found philosophy to be useful to for myself in similar ways. When I was diagnosed with the ocular tumour I near-immediately began writing a book project, which I am currently waiting to hear back from a publisher about, focused on "the revolt of the flesh" (to quote Albert Camus who I am again drawing from intensely), which has been a means of using philosophy as a therapeutic tool for myself. The result of this philosophical exploration is largely that of the affirmation of a preservationist aesthetic and ethic, which is at its core a yes saying to life wherever possible.

I feel now to return to the quotes from Stirner's *The Unique and Its Property*, which I started this piece with. Stirner and I have different focuses and concerns, and when he wrote the final section of that book he probably did not have health and disease in mind at all - though it is possible that he may have. Stirner mentions health, disease and illness, in the context of social and political arrangements, rather than as experiences that bring to attention the individuality and uniqueness of embodiment. My focus is different as the life I have lived and am living is different to Stirner's. The realness of health, illness and the possibility of death is phenomenologically plain to me, in ways that destroy ideals - all ideals are meaningless nonsense before the matters of health, illness and the possibility of death. My power, which is my life and possibility, is intensely plain with the experience of illness, disease/dis-ease and pain, with which I am thrust into an intense awareness of my individuality, my uniqueness, my differentiation, my being who I am.

As I come to the end of writing this, I am aware of my fatigue. In recent days I have been more active and have arguably pushed myself too much. This is painful to affirm and there is wisdom in this pain. If I want the pain to ease then I need to push less and go more gently. I believe I have succeeded in articulating what I sought to articulate here and am pleased to have written this in a

single sitting. This writing has not been written with any desire for pity or to suggest anything of victimhood. I do not resent my struggles and revolts, and engage with them gladly. The cry and revolt of my flesh, my embodied individuality and uniqueness in presence, calls out for possibility amidst illness and the dis-eases of this culture. Writing this has been therapeutically valuable for me and perhaps it is possible that it might be for another unique individual experiencing their own struggles with ill health, which is wonderful for me to affirm.

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