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**João
Florêncio**

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João Florêncio Title. *Essay*. Treatment. It's typed on its entirety, mostly on a laptop. Crisp Helvetica Neue, black. 12pt, double spaced. Sort of the way one would write an academic paper to read out loud somewhere where people are mostly thinking about the upcoming coffee break, yet still somehow manage to feign interest in what they're being told. The voiced dental fricatives (ð) and the laminal denti-alveolar plosives (ɖ) of the English language repeated over and over, and fading into each other.

I got fixated on this audio piece Steger did for *This American Life*... something about the mundanity of the text and the audio performance, the mundane everyday life of living with HIV and how this voice speaking from the past resonates with similar (in some ways) experiences of living with HIV today. My idea would be to start by taking on the structure of that audio piece, plagiarize its form as it were, use it to narrate some version of my own experience, and then use that as a springboard to discuss the ideas above.

Matthew Goulish This sounds perfect to me in so many ways. In any event, I am curious what Caroline and Lin think.

Caroline Picard I also love this idea! Can't wait to read it.

João Florêncio Great. Thanks.

Synopsis. The story concerns Luís, gay, white, Southern European, early 20s. Follows Luís on the day that he is informed of his HIV positive status in November 2007. It's both a period piece and a story about the present. Luís comes across as confident despite all the anxiety he's always lived with fearing he was undeserving, unable, not unlike Severin, the conflicted dominatrix character played by Lindsay Beamish in John Cameron Mitchell's *Shortbus*.

Locations. Victoria Line train interior. Pimlico station. Sexual health clinic waiting room. Sexual health clinic consultation

room. Vauxhall Bridge. Music. Strauss's lieder, particularly "Morgen!" sung by Waltraud Meier.

Un morgen wird die Sonne wider
scheinen
und auf dem Wege, den ich gehen werde,
wird uns, die Glücklichen sie wider einen
Inmitten dieser sonnenatmenden Erde...
und zu dem Strand, dem weiten,
wogenblauen,
werden wir still und langsam
niedersteigen,
stumm werden wir uns in die Augen
schauen,
und auf uns sinkt des Glückes stummes
Schweigen...

Some of the earliest scenes my memory can return are scenes of waiting: waiting at the hospital for appointments with the doctors, waiting to hear them say I'd finally get better that time around, waiting for surgeries, waiting to come back out of them, the slow ticking of post-operative time marked by the

dripping of morphine and tramadol into my veins, washing the pain away. Then there was the waiting of others: my parents, for instance, and the mother of the kid that once laid on the bed next to mine—pale, bald, and emaciated after another course of chemotherapy; his mother just sat there all day, holding his hand, waiting for the drugs to hopefully do their job. They are memories of waiting and they are memories of care. But they are also memories of boredom and the uneventful.

Life moved on but the waiting persisted: waiting for the bus, waiting in line at the supermarket, waiting for academic results, waiting for the job I've always wanted since those early hospital days, waiting for the results of new blood tests, waiting for a new diagnosis, waiting to start the drugs (back in those days you were still recommended to wait), waiting for the drugs to be delivered, waiting for them to take over and keep me alive, waiting for friends to get upset for me—upset on my behalf—waiting for them

to just get over it, waiting to get my head around the fact that I'm both ill and well... The dullness of it all is astounding; its repetitive pattern, the mesh through which life is threaded.

Lawrence Steger's contribution to the first episode of *This American Life* reminded me of the extent to which our lives remain so mundane despite the iron of illness having been burnt onto our skin. In that 1995 audio piece recorded for Ira Glass's award-winning radio show four years before his death, Lawrence's character Luke learns he is HIV-positive just before going on a road trip with his buddy Bill.

Lawrence Steger Cut to interior of car pulling out of parking lot. Luke keeps looking straight ahead, as he murmurs, "I'm positive." Long, slow pan from the back of Luke's head to the back of Bill's. There's no reaction in either of their faces or, better, the profiles of their faces. This is the longest shot. They don't look at each other.

[...] There's dead air. Cut to Luke's point of view. Car is pulling onto entrance ramp of highway. Luke sees hitchhiker with a sign that he scans for any remote meaning to the narrative. Luke sees himself outside of his own story. He can't read the hitchhiker's sign. He knows that he's on a long silent journey. He leans over to turn off the radio. Cut to black.¹

João Florêncio There is a passage in Pierre Bourdieu's *Outline of a Theory of Practice* in which the French sociologist describes an encounter with a woman of the Kabyle people, a Berber ethnic group native to Northern Algeria. In it, the woman notes the changes Western modernity brought to our understanding of illness and health.

Kabyle Woman In the old days, folk didn't know what illness was. They went to bed

1 Ira Glass, *This American Life*, ep. 1 ("New Beginnings"), Nov 17, 1995. Available at: <https://www.thisamericanlife.org/1/new-beginnings>.

and they died. It's only nowadays that we're learning words like liver, lung [*albumun*; Fr. *le poumon*], intestines, stomach [*istuma*; Fr. *l'estomac*], and I don't know what! People only used to know [pain in] the belly [*th'abut*]; that's what everyone who died died of, unless it was fever [*thawla*]... In the old days sick people used to call for death, but it wouldn't come. When someone was ill, the news soon spread everywhere, not just in the village, but all over the 'arch. Besides, a sick man's house is never empty: in the daytime all his relatives, men and women, come for news... At nightfall, all the women relatives, even the youngest, would be taken to his bedside. And once a week there was "the sick man's market" [*suq umutin*]: they would send someone to buy him meat or fruit.²

2 Pierre Bourdieu, *Outline of a Theory of Practice* (Cambridge: Cambridge University Press, 1977), 166.

João Florêncio The passage highlights, in an anecdotal manner, the enmeshment of illness and everyday life that was a feature of pre-state societies, including European ones. As twentieth-century thinkers as diverse as Walter Benjamin, Michel Foucault, or Zygmunt Bauman have argued, European Modernity and the developing bourgeois order that accompanied it, were grounded on a biopolitics of hygiene that sought to mark the bodies of the dead, the sick, and the abnormal, to then push them away from the “healthy” by placing them in mortuaries, asylums, clinics, and hospitals where death and disease were kept out of sight.

Walter Benjamin Dying was once a public process in the life of the individual and a most exemplary one; think of the medieval pictures in which the deathbed has turned into a throne towards which the people press through the wide-open doors of the house. [...] Today people live in rooms that have never been touched by death,

dry dwellers of eternity, and when their end approaches, they are stowed away in sanatoria or hospitals by their heirs. It is, however, characteristic that not only a man's knowledge or wisdom but above all his real life—and this is the stuff that stories are made of—first assumes transmissible form at the moment of his death.³

João Florêncio It is only through its engagement with death that a life can be performed orally in the shape of a story like the one we can still hear Steger tell in the archive of *This American Life*. According to Benjamin, storytelling is a form of narrative enacted in living speech and which draws from what he called “the epic side of truth”⁴ only accessible through lived experience. Normally

3 Walter Benjamin, “The Storyteller: Reflections on the Works of Nikolai Leskov,” in *Illuminations*, ed. Hannah Arendt (New York: Schocken Books, 1969), 93–94.

4 Benjamin, “The Storyteller,” 87.

speaking from a near-death position as an elder or a sick person, the storyteller tells stories drawn from experience and, through that, makes their stories the experience of those who are listening to their tale.

Steger's piece brings to mind Derek Jarman's film *Blue*, which was simultaneously broadcast on Channel 4 and BBC Radio 3 for its premiere in 1993. Both pieces are somewhat anticlimactic in that they foreground—in their storytelling—the ways in which experiences of living with HIV are deeply marked by the uneventfulness of the mundane everyday, the world of bureaucracy, of waiting, of street sounds, of navigating clinical settings, of navigating other people, of just trying to get through another day.

Lawrence Steger Stephanie has been saying something, and Luke has to blink his eyes again to refocus. He explains to Stephanie that he has been expecting this result, that he's experienced a large share of AIDS, cared for, and, likewise, buried lots

of friends. But it doesn't seem to come as a surprise. Stephanie says, "You can cry or hold my hand. I just want you to sit for a moment and let it sink in." Luke thinks, "Whatever."⁵

Derek Jarman Here I am again in the waiting room. Hell on Earth is a waiting room. Here you know you are not in control of yourself, wanting for your name to be called: "712213". Here you have no name, confidentiality is nameless. Where is 666? Am I sitting opposite him/her? Maybe 666 is the demented woman switching the channels on the TV.⁶

João Florêncio Still, unlike the first-person accounts in Jarman's film, Steger's piece exposes the artifice of storytelling itself, of how both Luke and the narrator are a construction of the artist and that none of them

5 Ira Glass, "New Beginnings."

6 Derek Jarman, *Blue*, Basilisk Communications Ltd., 1993.

are exactly Steger himself, an interest in the artifice of identity that we see developing as a motif throughout Steger's career. Namely: identity itself as a practice of plagiarism. At best, sampling.

Matthew Goulish Most of what I remember has folded over itself. New forms emerge out of old errors, the reckless with the rolodex, and here we are expending them, extending the idea for you, as an invitation. Your methods, your personas, your mysteries, your aggressions, your sources, your intellect, your generosity, your conviction, your humor—none of it makes that much sense really, or normal sense, or as the kids say now, normative.⁷

João Florêncio It was the failure to conquer mortality that led modern Europeans to focus their efforts on pushing it out of sight and rationalizing it through discovering,

⁷Matthew Goulish, *A Reckless Rolodex Reading Companion* (Chicago: Every house has a door, 2023), 12.

naming and fighting its surrogates, that is, diseases. In doing so, we were able to turn our inability to fight death into a long series of temporary victories over its various causes, from cholera to tuberculosis, COVID to HIV.

Do we have the Bauman ready? That one about hygiene and mortality?

Zygmunt Bauman Hygiene is [...] the product of the deconstruction of mortality into an infinite series of individual causes of death, and of the struggle against death into an infinitely extendable series of battles against specific diseases. This deconstruction being an attempt to exhaust the inexhaustible, an attempt doomed from the start and thus bound to suppress the knowledge of its own impossibility merely to be able to continue [...]. No hunting escapade is a conclusive one, no trophy final and ultimately gratifying. Hence the obsession, the tension, the hysteria that surrounds hygienic con-

cerns and activities. The dirt [...], bacteria, viruses, putrefying and thus surely toxic substances, all arouse intense fear and disgust [...], themselves surrogate outlets for the great metaphysical horror of mortality. Such irrational emotions, and the irrational practices they trigger are, again, the other side of the modern rationalization of death.⁸

João Florêncio Thanks to hygiene and its associated paradigm of immunity, illness went from being part and parcel of the everyday to becoming a divergence from the healthy norm of life. As such, it came to be understood as an exceptional, abnormal state of the body and started to be made sense of through spectacular narratives of overcoming, bravery, heroism, quest, remission, and ultimately restitution of health—the kinds of narratives that Steger eschews in his work.

⁸ Zygmunt Bauman, *Mortality, Immortality & Other Life Strategies* (Cambridge: Polity Press, 1992), 155.

Could we please plug that paragraph from *The Wounded Storyteller* here?

Arthur Frank The plot of restitution has a basic storyline: “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again.” This storyline is filled out with talk of texts and their interpretation, treatments and their possible outcomes, the competence of physicians, and alternative treatments. These events are real, but also they are metaphors in [the] sense of enacting the storyline of restoring health [...]. Metaphoric phrases like “as good as new” are the core of the restitution narrative. Such phrases are reflexive reminders of what the story is about: health.⁹

João Florêncio The problem with restitution and struggle narratives of illness is that, in presenting the latter as a state to be fought

⁹ Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* (Chicago: The University of Chicago Press, 1995), 77.

off with bravery and heroism, it presents illness as exceptional, as a bracketing of the idealized biopolitical standards of everyday life and the bodies they leave unmarked. The sick person—the chronic patient, the infected patient—comes to be seen and read primarily through their illness, as their illness. The sick person is put on a stage—medical, scientific, or mediatic—with the sole purpose of embodying that which the healthy body is not. In so doing, they are given a platform of visibility only under the condition that their story is one of striving back to the normative ideal of health—or at least one of dying trying. In their embodiment of a state perceived to be exceptional and therefore abnormal, the sick person’s visibility and their narratives of struggle and restitution help us define health through what it is not, thus reinforcing the norm of the living.

Lawrence Steger Cut to Bill in waiting room, flipping through *People’s The Year in Pictures*. Cut back to close-up of Luke, forehead wrinkled. He thinks his narra-

tor wants him to get out of the cubicle. He waits for Stephanie to finish her spiel, thanks her, and shakes her hand, getting a slight scrape from one of the fingernails. Close-up on Luke's hand, no scratch. The walls seem to pulsate as Luke walks down the hallway to the reception area. He tries to be as blank as possible to Bill.¹⁰

Susan Sontag But no change of surroundings is thought to help the cancer patient. The fight is all inside one's own body. It may be, is increasingly thought to be, something in the environment that has caused the cancer. But once cancer is present, it cannot be reversed or diminished by a move to a better (that is, less carcinogenic) environment.¹¹

João Florêncio It strikes me that Luke, in Steger's setting of his story, was both trav-

10 Ira Glass, "New Beginnings."

11 Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978), 15–16.

elling somewhere and also going nowhere. There was the hitchhiker with the sign to a possible end to the narrative Luke himself cannot grasp. It is fitting that a story about the death of the future is told in an episode of the show entitled “New Beginnings.” When you have nowhere to go you just wake up again every day, without fanfares, pathos or fireworks. Francis Poulenc’s *Mouvements Perpétuels*. The bass line of Kylie Minogue’s “Can’t Get You Out of My Head.” You’re going but you’re going in place. Wherever the body goes, the illness follows; and for as long as that body lives, loves, writes, desires or does anything else any other body would do, the illness will be there with it, living within it.

Rather than appearing as a state of exception, illness accompanies the unremarkable flow of the everyday, becoming part not only of the lived bodies of its carriers but also of their own lived subjectivity. There is nothing heroic about that, it is actually pretty unremarkable, boring most of the time. The more so in the context of chronic illnesses.

You know, sometimes we just wake up not feeling the need for a medal. *Morgen!*

Steger's contribution to the first episode of *This American Life* invites us to reflect on the unbearable familiarity of Luke's mundane, uneventful everyday—the unbearable familiarity of waiting, of staring, of feeling empty, of feeling nothing even when something happens that should make us feel something, about which we are expected to feel something. React, respond, articulate. Those are experiences we all recognize irrespective of how we imagine ourselves in relation to the binary of health and illness, irrespective of how we construct ourselves in relation to it. His work performs a counter-narrative of illness that does not present the lives and bodies of the unwell as particularly exceptional or heroic in order to be worthy of ethical consideration through some messed-up economics of compensation.

João Florêncio is Senior Lecturer in History of Modern and Contemporary Art and Visual Culture at the University of Exeter. A queer cultural theorist of the body, his interdisciplinary research focuses on visual cultures of sexuality, health and illness in relation to wider Western biopolitical, philosophical and technoscientific histories. He is the author of *Bareback Porn, Porous Masculinities, Queer Futures: The Ethics of Becoming-Pig* (Routledge, 2020).

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GALLERY 400