
H-France Salon
Volume 13, Issue 13, #7

**My Present Illness:
Fragments on Proust, Cancer and Death**

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for Leticia Nogueira (in memoriam)

The fragment is the intrusion of death into the work.
Theodor W. Adorno

Our worst fears, like our greatest hopes, are not [always] outside our powers, and we can
come in the end to triumph over the former and to achieve the latter.
Marcel Proust

1.¹

Philippe Lejeune proposes that, though autobiographies can be read as either a historical document or a psychological study, they are essentially a literary text. In *Roland Barthes by Roland Barthes*, the author (or narrator) cautions: “It must all be considered as if spoken by a character in a novel.”² Conceiving life as a narrative is a quintessentially Proustian coping mechanism. After all — and by all I mean thousands and thousands of pages of *In Search of Lost Time* — the novel’s narrator is certain that “real life, life finally uncovered and clarified,

¹ The idea of a collection of numbered paragraphs about Proust was borrowed from Anne Carson’s *The Albertine Workout* (New York: New Directions, 2014). By a perplexing coincidence, the first version of my text ended up with 59 numbered paragraphs, which is the exact same number of paragraphs of Carson’s text. Since editing, too, moves in a mysterious way, the final version of my work turned out one paragraph shorter than hers. I am also grateful to Roland Barthes, whose *Journal de Deuil* (Paris: Seuil/IMEC, 2009) was a loving and enlightening companion during the darkest times of the treatment, and my thinking and writing about it.

² Roland Barthes, *Roland Barthes by Roland Barthes*, trans. by Richard Howard (Berkeley: University of California Press, 1994 [1975]), epigraph.

the only life in consequence lived to the full, is literature.”³ The experience of stomaching a cancer’s return is barely literary, since “not all that happens in the belly | of the beast can be put into words.”⁴ Yet, some of us insist on turning to words, narratives, literature lest chemotherapy-curbed language leaves us with nothing but confining silence.

2.

Eight months after the end of my first cancer treatment, on 19 March 2020, I was diagnosed with an early recurring Hodgkin lymphoma. After several appointments with a team of haematologists, we decided to try a cancer protocol comprising an R-ICE chemotherapy regimen followed by an autologous bone marrow transplantation. At that time, I was re-reading the Doncières episode of *The Guermantes Way* for a book on Proust whose manuscript I have been meaning to send to the publisher since the very day the cancer nightmare began, that is, the day I got both a message from a publisher showing interest in my book proposal and was handed a CT scan exhibiting, for the first time, excrescently large lymph nodes in my chest.

3.

In the year the world was held captive by a deadly and unknown virus, we celebrated one hundred years of the publication of *The Guermantes Way*, the third novel of *In Search of Lost Time*. Its first part came out in 1920, shortly after the end of the Spanish flu pandemic. Its second part followed suit in 1921. One hundred years later, I come to grips with a stubborn, recurring lymphoma.

4.

Different from those facing a serious illness, a Proustian rarely feels forlornly alone, for no matter where they end up, there is always another scholar digging around the same subject, keeping them company. This is how I felt when I stumbled upon Thierry Laget’s unambiguous diagnosis of illness as the uniting force holding together the apparently disparate parts of *The Guermantes Way*, a book cleaved by death.⁵

5.

As a gravitational force, *The Guermantes Way* attracts a constellation of references to illness that seep through the ensuing volumes of the cycle: the illness and death of the narrator’s grandmother; references to the serious illnesses of two of the main characters, Charles Swann and Bergotte, who are both potentially suffering from cancer; the terminal illness of Marquis Amanien d’Osmond, the Duc de Guermantes’s cousin; caricatured depictions of four doctors, Professor E***, Dr Cottard, Dr Du Boulbon and Dr Dieulafoy; and loving and cruel accounts of healthcare.

³ Marcel Proust, *In Search of Lost Time*, ed. by Christopher Prendergast, 6 vols (London: Penguin Classics, 2003), VI: *Finding Time Again*, trans. by Ian Patterson, p. 204. All quotations by Proust are from this edition; some translations have been slightly modified.

⁴ “Nem tudo que acontece na barriga | da besta é possível por em palavras,” Lucas Matos, “Dentro da Barriga da Besta (Com Pieter Lastman),” *LunaPARQUE*, 11. All translations are mine unless otherwise stated.

⁵ See Marcel Proust, *À la recherche du temps perdu*, ed. by Jean-Yves Tadié, 4 vols (Paris: Gallimard, 1987–89), II, 1518.

6.

The poor health of the narrator's grandmother, mentioned in the opening of *The Guermantes Way*, is what has led the family to move into a new apartment in the Hôtel de Guermantes: "we had moved into it [this new home] because my grandmother was far from well (though we kept this reason from her) and needed cleaner air."⁶ Illness not only relocates the whole family but also the plot, interweaving with a story that is, first and foremost, about care — though an equally formidable testament to humankind's imaginatively uncaring forms of scoffing and belittling.

7.

Illness is always a source of movement, even when it paralyses or fastens the patient to a place — for instance, a bed or a hospital bedroom, as it is the case in a bone marrow transplantation. Throughout *The Guermantes Way*, illness is a force that, entangled with love, sets bodies and plots in motion.

8.

Illness, along with love and care, is the perfect ingredient of an effective yet costly literary remedy.

9.

All illnesses are equal, but some illnesses are more equal than others.⁷

10.

Getting the name of an illness right is a serious matter, whereas being able to say it aloud is often more serious.

11.

There are three conventional ways of referring to the disease I have: Hodgkin's disease, Hodgkin's lymphoma or Hodgkin lymphoma. The first form is a euphemism that comes in handy to those who don't want to face cancer too directly — as Proust was deeply aware, it's disturbingly common to avoid the word cancer when talking about it. The second form is misleading, as British physician Dr Thomas Hodgkin (1798–1866), who was affiliated with Guy's Hospital — which is part of the same university with which I, too, happened to be affiliated when I fell ill — did not suffer from the disease he pioneeringly describes in his 1832 paper titled "On Some Morbid Appearances of the Absorbent Glands and Spleen." The third spelling is the exact one.

12.

Deleuze explains that "when a doctor gives his name to an illness this is a major linguistic and semiological step, inasmuch as a proper name is linked to a given group of signs, that is, *a proper name is made to connote signs*."⁸ Being able to summon a symptomatology, to enter a world of signs, is not, however, the only reason why we should get the name of an illness

⁶ Proust, *The Guermantes Way*, trans. by Mark Treharne, p. 8.

⁷ Susan Sontag, in her seminal essay *Illness as Metaphor*, astutely states that "particular diseases figure as examples of diseases in general; no disease has its own distinctive logic," *Illness as Metaphor and AIDS and Its Metaphors* (London: Penguin, 2013 [1978]), Kindle.

⁸ Gilles Deleuze, *Masochism: Coldness and Cruelty*, trans. by Jean McNeil (New York: Zone Books, 1989), p. 16.

right. A proper name is also an affective and mnemonic key. As Barthes wonderfully puts it, “a proper name is, somehow, the linguistic form of recollection.”⁹

13.

Before finding out about Swann’s illness at the very end of *The Guermantes Way*, the narrator learns that the Duc and the Duchesse de Guermantes had returned to Paris on the eve of the Princesse de Guermantes’s reception, not for the reception itself but because a cousin of theirs was ill.

14.

Between the Marquis d’Osmond, the cousin of the Guermantes, and Swann, the episode of the red shoes, that is, the final episode of *The Guermantes Way*, takes place entirely under the sign of illness (as well as the socially codified hurtful responses to it).

15.

Swann’s illness is mentioned for the first time during a symptomatic dialogue between Swann and the Duchesse de Guermantes. Having declined her invitation to join her for a holiday in Italy, Swann is interpellated by a displeased Duchesse, who seeks to understand his turning down of her entreaty. After a hint from Swann, the Duchesse realizes that he is unwell: “I don’t think you look at all well, and it pains me to see you so off-colour.”¹⁰ Torn between friendship and social obligations however, she eschews engaging in Swann’s suffering and rushes off asking: “Will you tell me in one word why you can’t come to Italy?” Embarrassed, Swann circumvents the word *cancer* — the one word he is unable to utter — and smiles providing a gloomy answer: “But, my dear friend, it’s because I shall have been dead for several months by then. According to the doctors I’ve consulted, by the end of the year *my present illness* — and as far as that goes it could carry me off at any time — will leave me three or four months to live at the most, and even that is an optimistic estimate.”¹¹

16.

At no point in the whole conversation does the word cancer appear.

17.

Barthes claims that a proper name is the source of different forces: “the power of essentialization (since it indicates only one referent), the power of citation (since we can call at our discretion all essence stored in the name by pronouncing it), the power of exploration (since we “unfold” a proper name exactly the same way as we do with a recollection).”¹² Proper name’s ever-growing, multivalent nature might be the reason why, when it comes to a serious illness, the narrator, Swann and most of the people I encountered during my illness refrain from calling a spade a spade.

⁹ Barthes, “Proust et le noms,” from *Nouveaux Essais Critiques*, in Barthes, *Œuvres complètes*, ed. by Éric Marty, 5 vols (Paris: Seuil, 2002), IV, 66–77 (p. 69).

¹⁰ Proust, *The Guermantes Way*, p. 594.

¹¹ Proust, *The Guermantes Way*, p. 594 (my emphasis).

¹² Barthes, “Proust et le noms,” pp. 68–69.

18.

Did Swann know at that point that he had cancer? Probably. It is likely that he omitted it because he knew it would be senseless or, worse, demoralising to share it with the Guermantes. But why does he not talk to the narrator about it?

19.

Was it politeness that prevented Swann from imposing his needs on his friends or from saying the name of his illness? After all, social conventions always haunt the experience of being ill — and Proust cunningly capitalizes on it.

20.

Is it possible to count how many roles *fear* plays in the drama of being ill?

21.

Empathy is customarily defined as the ability to put oneself in the place of others. By contrast, the Duc de Guermantes is the epitome of the subject incapable of experiencing empathy in the novel — today, he would probably be diagnosed with Narcissistic Personality Disorder. While his lack of empathy amounts to (not so well) concealed spite at the end of *The Guermantes Way*, his unempathetic defining feature is first noticed during the grandmother's illness episode, when the narrator describes him as "one of those men who are incapable of putting themselves in the place of others."¹³

22.

People often feel the desire — some, the burden — to offer help to those grappling with a serious illness. Those who genuinely *want to help* offer their help at your discretion. Those who, instead, *want to feel helpful* lecture you on how to best tackle your own illness. Imperative advice on which doctor to see — of the sort of the Duc de Guermantes's with regard to Doctor Dieulafoy — was a defining feature of all members of the latter group I had encountered while undergoing treatment for cancer. "Make an appointment with specialist Y," they would instruct me, "he is *the* authority in oncology of Belo Horizonte." Another person would let me know that a doctor who saved a friend of hers would most certainly save me too. As the narrator disingenuously notes, "this is the sort of thing society people say about their doctors, and we believe them, just as Françoise believed newspaper advertisements."¹⁴ The risk is that, in their haste to be helpful, people might overlook the specifics of your illness, quickly pointing you to a pulmonologist instead of a haematologist simply because your swollen lymph nodes are located in your chest.

23.

Be it social conditioning, a way of deflecting responsibility or a projection of their concern with your health, a number of people feel it is *their* responsibility to remind you of *your* responsibility towards *your* illness. Microfascist statements, their orders flood the patient's routine, drowning them in ever more bitter waters. By regurgitating facile platitudes — "Think positive!," "Have faith!," "Don't think about it!" — which rarely coincide with the patient's needs or desires, they show what Proust would call "excessive or inadequate expressions of sympathy."¹⁵

¹³ Proust, *The Guermantes Way*, pp. 336–37.

¹⁴ Proust, *The Guermantes Way*, p. 322.

¹⁵ Proust, *The Guermantes Way*, p. 323.

24.

By lecturing a sick person, some people seem to be hoping to exempt themselves from engaging with the sick person's darkness and dreads. As if fearing more than the patient themselves for the patient's life, they hasten to stifle, hush or silence any humming, murmur or noise that might offer a glimpse into the darkness that the sick person visits and revisits, mourning and weeping, when unwell, exhausted and in pain. "Think positive" and its kindred formulations are a *sésame, ferme-toi* (close sesame) that locks the patient inside a cave that is filled not with treasures, but guilt, suffering and pointless, labyrinthine thinking — am I unwell because I do not want to be well? Is illness a failure of willpower? Is its cure the result of it? Is it enough to think positively? Is having faith really what saves you? And what is it to think positively? Is it to wish a quick death for yourself so that suffering would expediently go away, or naïvely silver-lining the terrible, complex reality in which you are entrapped?

25.

For the sick person, help very often comes as silence not silencing, or rather as lending an amplifying, accommodating ear to their complaints and laments. More often than people would think, a bemoaning patient is not asking for a solution but for support. They are not looking for an enlightened Virgil, an omniscient guide who will lead them through hell, for every sick person's hell is different. Their geography mirrors neither Dante's charted *Inferno* nor the graphic, simpleminded accounts of discomfort, pain, anxiety and depression that proliferate, not unlike cancer, in the rapidly changing social world and the world of social media, where everyone seems to have the answer or to know the way. The patient might crave companionship of the kind of a cave, but one that provides shelter and which, by resonating with the patient's worries and fears, creates an echo that, in eventually fading away, might bring quiet and peaceful comfort.

26.

Someone who seems to understand the value of silent companionship for those who are ill and their family is Bergotte. Even after falling seriously ill himself, the celebrated fictional writer of *In Search of Lost Time* will visit the narrator every day, spending several hours with him during the illness of his grandmother. As the narrator notes, falling ill has drastically altered his behaviour: "But in the past he had come in order to talk without being interrupted; now he came to sit in silence for long periods without being asked to say anything. For he was very ill, with albuminaria like my grandmother, some people said. According to others, he had a tumour."¹⁶ He speculates that this change in Bergotte's demeanour was due to his "growing weaker by the day; he found it difficult to climb our staircase and even more difficult to go down. [...] His eyesight had completely gone and he often had difficulty with his speech."¹⁷ The narrator is, however, oblivious to what had changed in Bergotte's mind, the perspective on being ill he had acquired first-hand.

27.

The narrator reminds us that "it has been said that silence is a powerful weapon."¹⁸ The silence caused by memory loss, one of the side effects of chemotherapy I have been increasingly experiencing — absent familiar words, friends erased from affectively charged episodes of my life, entire folders of memory deleted — is as much a sorrow as it is a

¹⁶ Proust, *The Guermantes Way*, p. 323.

¹⁷ Proust, *The Guermantes Way*, pp. 323–24.

¹⁸ Proust, *The Guermantes Way*, p. 118.

powerful weapon I wield in order to dampen the excessive and unnecessary chitchat and excrescent discourse about cancer that has overwhelmed me since the diagnosis — this “obliterating noise.”¹⁹

28.

Social habits imply that a grave illness must not be faced head-on and in plain sight. Speaking of it out loud, for instance, might be rude or hazardous, since a passing mention might be enough to summon it in its full force. The narrator’s grandmother tries to conceal her stroke from him. The Duc de Guermantes tries to convince Swann that his illness is the invention of his ass of a doctor: “They’re fools” (*ce sont des ânes*), his stentorian voice shouts at a departing Swann in the very last paragraph of the novel.²⁰ And, for a long time, my father couldn’t utter the word *cancer*, let alone in tandem with my name.

29.

Different from the illness, which observes no moral code, the sick person can feel shame in the face of their debilitating condition, be too scared to talk about it or believe that words are futile against the tyranny imposed by their illness. After all, what can a sick person get from saying out loud the name of their illness apart from a painful reminder that often strikes as a death knell?

30.

We are taught to dissociate assertion and conviction from suffering, and we are taught to associate shame with it instead.

31.

The narrator’s grandmother tries to conceal her stroke from him. In face of a serious, debilitating illness, the sick person generally follows one of the two paths: hiding their condition or exposing it. The reasons for adopting either attitude are plenty. A century, an ocean and a fiction away from the narrator’s grandmother, I decided not to hide any sign of debility and weakness my condition would bring. Showing I was ill was, to me, a way of making a statement against the utilitarian and exploitative idea that our bodies must never fail. A fellow bone marrow transplantation patient, however, chose to behave differently. Though she had been trying to post daily updates on her Instagram account, things had got difficult for her. She then posted a quick video explaining her sudden disappearance, saying that she would not be posting as usual because she preferred to share only uplifting and positive content. Her final words in the video struck my ears as one of the many moralising lessons bestowed upon us by the narrator’s grandmother or, for that matter, Mme de Sévigné: “to suffer, we do it alone, quietly.”

32.

Oblivious to moral imperatives and social codes, serious illnesses are unashamedly disruptive and, despite not being invited, settle where they see fit.

¹⁹ Anne Boyer, *The Undying: Pain, Vulnerability, Mortality, Medicine, Art, Time, Dreams, Data, Exhaustion, Cancer, and Care* (New York: Farrar, Straus and Giroux, 2019, Apple Books), p. 13.

²⁰ Proust, *The Guermantes Way*, p. 597.

33.

When I was diagnosed with a recurring lymphoma, I had to decide without further ado how to deal with it, which is not to say that I had to choose between being an optimist or a pessimist. Deciding on a protocol to treat a recurring cancer is challenging, as there are usually a few possibilities and far too much to be taken into account. This is why doctors often confer, as my doctors did, in order to elect what would be the best course of action. But before going for one or another protocol, we patients must decide whether or not to embrace allopathy, all of that while being bombarded by friends, acquaintances, ex-patients, friends and family members of ex-patients with ideas for alternative treatments, special diets and religious guidelines. Though medicine might not be an exact science, as Proust says, it is still a science. Therefore, I share his perception that trusting it is better than not trusting it. In his words: “For, medicine being a compendium of the successive and contradictory mistakes of doctors, even when we call in the best of them, the chances are that we may be staking our hopes on some medical theory that will be proved false in a few years’ time. So that to believe in medicine would be utter madness, were not to believe in it a greater madness still, for from this accumulation of errors a few valid theories have emerged in the long run.”²¹

34.

Proust is unequivocal: “Medicine is not an exact science.”²²

35.

In Proust’s universe, medicine frequently overlaps with the art world. Neurologist, psychiatrist and one of the leading doctors of *In Search of Lost Time*, “Du Boulbon was at heart an artist.”²³ This perception comes from the fact he, who had been recommended by Bergotte, was “a practitioner who would not bore [the narrator], who would discover methods of treatment which, however strange they might appear, would adjust themselves to [his] particular way of thinking.”²⁴

36.

The sick person’s utopia: doctors who would adjust themselves to our particular way of thinking.

37.

Medicine is an art of war.²⁵

38.

Cancer is surrounded by the rhetoric of war. People speak of “fighting” or “battling” cancer and of a patient as “soldiering through” the treatment. Though people rarely speak of those who are killed by cancer as casualties, the idea of beating or defeating cancer as well as the depiction of a patient who finalized his treatment as a survivor are stereotypical. Proust is not alone in likening the treatment of a serious illness to a form of war, though he inventively likens doctors to military strategists instead of resorting to the traditional analogy that equates

²¹ Proust, *The Guermantes Way*, p. 295.

²² Proust, *Sodom and Gomorrah*, trans. by John Sturrock, p. 48.

²³ Proust, *The Guermantes Way*, p. 456.

²⁴ Proust, *The Guermantes Way*, pp. 296–97.

²⁵ Sontag, in *Illness as Metaphor*, and Boyer, in *The Undying*, masterfully comment on several links between medicine, military metaphors, cancer and warfare.

patients with soldiers. Doctor Cottard, “this unprepossessing, commonplace man,” becomes “a general who, while unexceptional in all other respects, is a gifted strategist and, at a time of crisis, after a moment’s reflection, can decide upon the wisest course of action in military terms and issue the order: ‘Advance eastwards.’”²⁶

39.

Comparing a doctor to a strategist and their medical deliberation to a military course of action seems rather fitting, since the convalescing body, rather than a fighting subject, is treated as a battleground where the war on cancer is waged. During a bone marrow transplantation, your body somehow stops being yours, and is converted into the field where the battle between medicine and cancer takes place. As the landscape has an impact on the outcome of the combat, you are not entirely deprived of agency. Yet, you lose so much control of your body that it surely feels as if you had lost your agency entirely. You are reduced to a country teetering on the brink of destruction. Caught in the middle of a firefight between the enemy (cancer) and the allied army (the doctor with their soldiers, the nurses, and their artillery, the medication), your healthy cells fall, together with your mental health, like civilian casualties of both forces. In the event of a truce or the cessation of the conflict, they will be the ones who will have to deal with the onus of rebuilding this war-torn land.

40.

Occasionally, a metaphor hides a buried truth. The First World War brought about a hiatus in the publication of *In Search of Lost Time* that allowed for crucial editorial replanning on Proust’s part.²⁷ Among the results of the war-period editing are the introduction of the character of Albertine and the placing of the grandmother’s illness and death as the pivot on which *The Guermantes Way* hinges. The First World War also ushered in perverse chemical innovations, such as mustard gas, a weaponized poisonous substance developed by 1918 Nobel Prize winner, chemist Fritz Haber. On the eve of the Second World War, in search of an antidote for mustard gas, scientists Louis Goodman and Alfred Gilman observed a potential relation between mustard gas, white blood cells and blood cancer such as leukaemia and lymphoma. On 27 August 1942, a patient who entered the annals of medicine simply as J. D. and who was then suffering from advanced lymphoma was experimentally administered nitrogen mustard, the compound originally used to produce mustard gas. Though J. D. died six months after the experimental treatment, his clinical conditions improved considerably after a few doses of the poison, which marks the beginning of what we today call chemotherapy.²⁸ Research on nitrogen mustard allowed for the development of derived drugs such as carboplatin, one of the drugs comprised by the chemotherapy regimen I used in order to treat recurring Hodgkin lymphoma. Artillery has literally become medication.

²⁶ Proust, *The Guermantes Way*, p. 320.

²⁷ Mark Treharne, “Translator’s Introduction,” in Proust, *The Guermantes Way*, pp. vii–xiii .

²⁸ Sarah Hazell, “Mustard Gas: From the Great War to Frontline Chemotherapy,” <https://scienceblog.cancerresearchuk.org/2014/08/27/mustard-gas-from-the-great-war-to-frontline-chemotherapy/>, accessed December 18, 2020. See also, “Discovering Early Chemotherapy Drugs,” < <https://www.icr.ac.uk/about-us/our-achievements/our-scientific-discoveries/we-discovered-chemotherapeutic-agents-which-are-still-in-use-more-than-50-years-later>>, accessed December 18, 2020.

41.

If cancer brings about any kind of war, it is, for certain, a civil war. I wage war against my own body, a conservative war against radical change. In this dangerous war, my body is deviously a warrior, the enemy, the battlefield. How can I be both the threat and the saviour? Would I be a kind of god?

42.

Proust's description of the grandmother's illness provides a glimpse into the awkward role of the body in cancer treatment: "The blows we aimed at the evil disease which had settled inside her [the grandmother] always fell wide of the mark; it was she, it was her poor body standing in the way that became the target."²⁹ The body of any cancer patient, for better or worse, always stands in the way.

43.

After fighting a war on cancer, I want now to settle so as to create. This time, I do not want to work in order to rebuild an old, devastated country. I would rather be another country. No more rebuilding.

44.

Being diagnosed with cancer is, before anything else, managing the idea that you are ill and that your illness, though unpredictably dangerous, might not be a death warrant. The news of cancer hardly strikes as the simple news that you have fallen ill. Rather, it gives rise to an over-accelerated, replicating cluster of frightening fantasies. In addition to their clinical condition, a cancer patient grapples with overgrown psychological and nervous responses to the fact they have been told they have cancer (or cancer has them):³⁰ "for every one disorder that doctors cure with medication (it does happen occasionally, I'm told) there are ten others they provoke in healthy [as well as in unhealthy] patients by inoculating them with that pathogenic agent a thousand times more virulent than all the germs you can name, the idea that one is ill."³¹ These creeping psychological disorders are, a great deal, the side effect of a socially constructed notion.

45.

For the narrator, cancer does not cause death. Rather, death causes cancer. In his eyes, there isn't a single death but plenty, for "there are almost as many deaths as there are people."³² Each death is singular; that is, the accomplishment of a single death's task of ensuring that every living being eventually meets their end.

46.

Hereafter, I will capitalize the word Death since I, like the narrator, prefer to think of it as a subject deserving of a proper noun and gender — which varies according to the choices of a culture, a religion, a poet, a painter, regardless of the rules of grammar.³³ Gifting it with a

²⁹ Proust, *The Guermantes Way*, p. 320.

³⁰ Cf. Boyer, *The Undying*, p. 145.

³¹ Proust, *The Guermantes Way*, p. 299.

³² Proust, *The Prisoner and the Fugitive*, trans. by Carol Clark and Peter Collier, p. 180.

³³ See Karl S. Guthke, *The Gender of Death: A Cultural History in Art and Literature* (Cambridge: Cambridge University Press, 1999).

name and a gender seems an effective way of making it seem more human. Uncannily similar to us, it becomes less threatening, even friendly.

47.

Akin to Death — or because it is a ruse of Death — a serious illness is seen in Proust's novel as a "friendly" neighbour who is quick to make itself known to the sick person. However, he notes, "it is a terrible acquaintance, less for the suffering involved than for the novel strangeness of the terminal restrictions it imposes on life."³⁴ Adapting to life as a patient is, perhaps, one of the most challenging aspects of being seriously ill — and it is twice as difficult to readapt to the life of a healthy person when your cancer treatment is successful. After treating cancer twice, I can attest to the intractable challenges involved in resuming what people call a normal life, a life shaped by normal and exploitative working hours and relentless social interactions. People avoid talking about the nights disrupted by the creeping feeling that cancer might be growing again heedlessly inside you, by the fear of your unhinged neighbour being back. People praise you as they would do a war hero who had just performed a feat, before swiftly asking you about jobs and projects, as if a cancer treatment were not radically disruptive, as if your body and, often, soul had not lost all desire to live. People expect that surviving cancer would induce a state of elation, as though surviving cancer treatment were the same as waking up from a nightmare, an utter relief. It is not, for the nightmare was all too real and might never be over.

48.

The Proustian narrator sees cancer as a trick Death, who seems to be female since the narrator compares her to a nun, plays on us to carry out her job. In his words, cancer is a sort of device implanted in us to make sure that we will die. The deadly device does not have to be cancer, for sure, since Death is resourceful. However, the device implanted in Swann, as the one implanted in me, was. Again, Swann, like me, had it twice. He died. I am still alive. Maybe the Death "sent by fate to release" me is currently engaged in other business.³⁵ Something of which I cannot ever be sure, for, as the narrator reminds us, "we lack the sense which would allow us to see them passing with great speed, flying in all directions, the various deaths, the active deaths sent by destiny after this man or that."³⁶

49.

Eventually, as a sanctimonious sister, Death will return for the last rites — "then, a few minutes before one breathes one's last, death, like a nun who had been nursing rather than destroying one, comes to witness one's last moments and to set a final, crowning halo upon the being, now frozen for ever, whose heart has stopped beating."³⁷

50.

Death is a caring presence nursing us all along, since we are her responsibility. More than sorrow, she gives us purpose, and our passing is nothing but a final act of care, a coronation whereby we finally become the absolute sovereign of our lives. Once dead, nothing more changes in our lives against our will. The vicissitudes of life are over. Death is the definitive face of control.

³⁴ Proust, *The Guermantes Way*, p. 314.

³⁵ Proust, *The Prisoner and the Fugitive*, p. 180.

³⁶ Proust, *The Prisoner and the Fugitive*, p. 180.

³⁷ Proust, *The Prisoner and the Fugitive*, pp. 180–81.

51.

The refreshing idea of a freezing corpse with no more desires.

52.

Death always takes us by surprise. One can die in a car crash or be diagnosed with a terminal illness. Though you might die long after your diagnosis, the surprise is handed to you the moment you are given it. When you sit across from a doctor and hear them utter the word cancer, you inevitably feel the grip of Death on your body and soul. At that moment, you realize what you always knew, “that death can come at any moment” and that that moment could be that very afternoon.³⁸

53.

As the treatment unfolds, you realize that no matter what outcome, Death will not loosen its grip on your soul.

54.

Though everyone suffers, we are educated to conceal suffering. From a very early age and almost tacitly, we are taught that suffering should be kept private. We are taught to deny suffering and sadness, and given the impossibility of its full denial, we are taught to hide it and parsimoniously share it with only a few. For suffering is ugly. It coerces us into attentively looking powerlessness and hopelessness in the eye. Suffering can bring the worst on us by revealing the worst in life. Yet it puts us in touch with unheard-of dimensions of our experience.

55.

We all suffer. Swann has suffered. The grandmother has suffered. I suffer. And yet we are often denied the right to face and embody suffering’s ugliness lest it be construed as failure, weakness or, worse, rudeness — for suffering is, in many ways, a nuisance. Regaining our ability to suffer publicly might be a form of stressing the positive side of this inescapable dimension of human experience. By expressing unashamedly our suffering to others — to everyone — we may not only free unknown forces of pleasure but also challenge a society shaped by the denial of suffering — a utilitarian society that denies it not because it wants to overcome it but because suffering undermines its “healthy” functioning. (See how we are dealing with the Covid-19 pandemic.) We are not prepared to suffer. We are not taught how to suffer. And mainly for this reason, we must struggle with our suffering alone. We fail to understand that suffering is neither a flaw nor a virtue, neither a circumstance nor a value, but one of the substances of which life is made.

56.

Because we don’t know how to suffer, during my transplantation I struggled alone in my uncreative white hospital room. My mother was by my side, but because I learned that suffering is a private matter, I did not cry in front of her — or at least tried not to. I did not do so because I knew that my suffering would have triggered or amplified her suffering and, for some prudish reason, I restrained myself from letting my suffering surface the way it should have, as shouts, cries, weeping, screams, things being broken. I *behaved*. I pulled myself together. I didn’t lose it. I wrote it down. I didn’t call any of my friends to tell them off for

³⁸ Proust, *The Guermantes Way*, p. 312.

allowing me to suffer alone. I did not do it because it was not reasonable or accepted. I did not do it because I was taught that this is not their responsibility. And besides, what could they have done? Suffered alongside me? Were they not suffering already?

57.

“Not once did she [the narrator’s mother] raise her eyes to the sick woman’s face” — staring directly at the ugliness of a serious illness comes across as cruel.³⁹ The narrator enumerates a set of possible reasons for his mother’s downcast eyes: “Perhaps this was to prevent my grandmother from being saddened by the thought that her daughter had been alarmed by the sight of her face. Perhaps from fear of pain so excessive that she did not dare to confront it. Perhaps out of respect, because she felt it unacceptably impious to take note of any trace of mental debilitation on that revered face. Perhaps to be better able to preserve intact in her memory the true face of her mother, beaming with intelligence and kindness.”⁴⁰

58.

Those we encounter along our Calvary almost invariably avert their gaze and try not to look straight at us lest their facial reactions betray their composure in the face of the commonly disheartening or disturbing sight of a sick person, a person who might be seen as not being themselves any longer. The ocular tension is, however, instantly perceived, and would have been more easily endured if confronted literally head on. We all might benefit from some fearlessness and naturalness in front of a decaying body, like when your three-year-old goddaughter asks, “where’s your hair?” This is not, however, the same as commenting “My goodness! You look ill!” when you are indeed ill. Spontaneity and denunciation or, in theological terms, confession and condemnation are diametrically opposed ways of meeting an illness.

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H-France Salon

ISSN 2150-4873

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³⁹ Proust, *The Guermantes Way*, p. 317.

⁴⁰ Proust, *The Guermantes Way*, p. 317.