

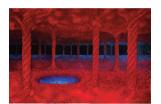


Volume 13 Issue 2

## On the cover: The Gateway by Antar Mikosz

The cover image on this issue of Ars Medica is used by permission of The American Museum of Visionary Art, Baltimore.

Please view alongside the poem "At the American Museum of Visionary Art: The Gateway" by Marjorie Maddox Hafer, appearing in this issue of Ars Medica.







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Volume 13 Issue 2

#### **Editorial**

Moving Together from Our Past to New Opportunities

Ars Medica is pleased to partner with the newly formed Canadian Association for Health Humanities/L'Association Canadienne des Sciences Humaines en Santé (CAHH/ACSHS). Below, the executive of CAHH/ACAHS offers an overview of the new association and a call for participation.

The existing Canadian health humanities community already recognizes that human health and illness are fundamentally informed by and anchored in both the sciences and the arts. Notable today is that Canada has *finally* established a national association focused specifically on humanities in health: we say "finally" because many other countries, including the United Kingdom and the United States, have had associations to address the health humanities for decades (Bleakley, 2015; Jones & Carson, 2003).

The newly established Canadian Association for Health Humanities (CAHH), funded by a gen-

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erous grant from Associated Medical Services (AMS), was officially launched in Halifax in April 2018. The CAHH is rooted in the lessons and work of the Canadian community of practice that has coalesced over the past decade around the annual Creating Space meetings as well as other local health humanities associations. That community's work has clearly established the health humanities as a growing and international field of inquiry and practice, a field that recognizes that arts (e.g., poetry, painting, theatre) and humanities (e.g., philosophy, literary studies, history, ethics) are means of expressing and promoting human health and wellbeing and of understanding and ameliorating suffering. The health humanities do not, of course, work against health sciences; instead, health humanities investigate and extend an understanding that factual, objective, or positivist knowledge about human health can be strengthened with knowledge that focuses on the experiential meaning, emotion, aesthetics, and values of well-being.

As one of the first summative papers about humanities in Canadian medical education observed some years ago, the health humanities are present in many places, often with all good intentions; there is not, however, a great deal of consistency about what is meant by the health humanities, nor is there consensus about their utility (Kidd & Connor, 2008). The CAHH can neither solve fundamental uncertainties about the utility of humanities to human wellness and illness nor eliminate the ambiguity that accompanies the experience of being human. What the CAHH can do, and is com-

mitted to doing, is build on the strong initiatives developed for many years in many places by delving into that ambiguity and promoting the exchange of knowledge, ideas, and critical dialogue about the health humanities among scholars and practitioners in Canada. The CAHH can and will foster collaborative explorations of the health humanities nationally and internationally, especially by hosting and supporting meetings, publications, and related activities. At present, our key conference is Creating Space, at which we will hold our annual meetings. We are pleased to continue to the support begun by the AMS of this journal, Ars Medica. Fundamentally, the newly established CAHH seeks to facilitate initiatives and interdisciplinary, cross-professional inquiry into research, education, and clinical practices relevant to the health humanities.

What, some readers might well be asking, does this look like on the ground and in practice? How, others might wonder, does this impact me? How can I help?

In other words, Canadian health humanities? So what?

The good news is that many concrete examples exist in Canada of actualizing the health humanities. Documenting and disseminating these examples is part of what the CAHH will do. Clinicians and healthcare professionals across the country are increasingly turning to humanities-based approaches in efforts to thwart burnout or increase patient-centred care (Fraser, 2018; Wald, 2015; Yoo, Matos, Bota, Schrewe, & Armstrong, 2019).

Similarly, we have seen the rise of narrative medicine, a practice that foregrounds stories and empathy about the illness experience, as practitioners look for efficient, socially accountable ways of understanding patients (Charon, 2001). Growing numbers of health researchers and practitioners gather every year at the Creating Space conference to share their innovations and ideas about the health humanities. The desire and need for the health humanities have percolated into medical education, with undergraduate and postgraduate medical learners increasingly being asked to engage in creatively informed reflective practices. Patients, their families, and others who wish to explore instances of illness and health are also demonstrating desires to express their ideas creatively.

The fact is that we live in a rapidly changing world, a place in which pluralistic, transformative processes such as the Truth and Reconciliation Commission of Canada have emerged at the same time as intolerance, demagoguery, and populism are seemingly spreading like a brushfire across liberal democracies. The humanities offer not only intellectual space to explore empathy and advocacy in creative ways (Gaufberg, 2017) but serve as a firewall against the collapse of that respectful, considered space itself. How, then, might we best use the health humanities to inform ourselves and others, in the service of building and maintaining strong, inclusive communities?

As with anything new, there are challenges associated with the unknown, with uncertainty, with a lack of set-in-stone or evidenced clarity. Yet all of

these question marks are equally accompanied by exclamation points indicating the tantalizing promise of this unknown. How can—or should—the health humanities be tailored to a Canadian context? Can the health humanities be used to think through uniquely Canadian realities, such as our strong and growing Indigenous population or our huge and varied physician geography? How can the health humanities be adapted to reflect the distinctly Canadian realities of delivering a universal healthcare plan amid inter-provincial/territorial jurisdictional tensions? Why and where might Canadian health education take up the health humanities in a more robust, integrated fashion? Why should Canadian healthcare professionals care, and if they do, what is to be done?

It will be the role of the recently established CAHH to assist in answering these (and so many other, as yet unidentified or unclear) questions. Members of the CAHH's inaugural executive will be looking for answers and expertise from people interested in the health humanities from coast to coast to coast. We hope you will be among them.

#### Website

Canadian Association for Health Humanities, www.cahh.ca

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# Doctors as Patients: An Interpretative Study of Two Literary Narratives

Jonatan Wistrand

#### **Abstract**

Medical practice could be described as a drama in which doctors and patients are two actors with different roles to play. While doctoring has traditionally been regarded as a rational and reliable activity, patienthood has been characterised by compliance with, and confidence in, the medical system. However, when doctors become ill this dichotomisation of medical practice is challenged. The aim of this article is to examine how that challenge has been described in literature. By interpreting one autobiographical work—A Leg to Stand On (1984) by Oliver Sacks—and one fictional—A Country Doctor (1919) by Franz Kafka—the phenomenon of the ailing physician is exemplified and explored through narrative analysis. In the fictional, as well as in the autobiographical, narrative the "doctor as patient" is primarily presented as a paradox and a deviation from normality. After recovery, however, doctors' illness experiences are regarded as a valuable resource in their continued medical practice.



Dr Ridgeon: The most tragic thing in the world is a sick doctor.

Dr Walpole: Yes, by George: it's like a baldheaded man trying to sell a hair restorer.

The Doctor's Dilemma
– George Bernard Shaw (1906)

In contemporary studies based on questionnaires and interviews, doctors' management of their own illnesses is described as a greater challenge than treating patients in their daily practice (Kay, Mitchell, Clavarino & Doust, 2008). Extensive self-medication and hasty corridor consultations, resulting in imprecise diagnoses and blurred medical responsibility, are well-documented phenomena (Campbell & Delva, 2003; Fridner, Belkic, Marini, Gustafsson Sendén & Schenk-Gustafsson, 2012; Ingstad & Christie, 2001). The plight is complex, but one contributing factor seems to be an uncertainty as to how the role of the patient might be combined with the doctor's own professional identity (McKevitt & Morgan, 1997a).

The aim of this article is to explore the sociological understanding and personal experience of the ill physician through hermeneutic analysis of literary testimonies. Subsequently two narratives are interpreted: A Leg to Stand On (1984) by Oliver Sacks and A Country Doctor (1919) by Franz Kafka. These works have been chosen since they both describe, in a particularly illumining manner, different and complementary aspects of the events and emotions unfolding when doctors themselves



become patients. Furthermore, these two narratives together span a spectrum from the autobiographical to the fictional. Drawing on the notion of Paul Ricoeur that "fiction, in particular narrative fiction, is an irreducible dimension of 'self-understanding'" (Ricoeur, 1991, p. 31), it is presumed that both fictitious and biographical descriptions might guide us to a more profound understanding of illness experience among physicians. In that sense this article follows a methodological tradition from recent decades, advocated by scholars such as Rita Charon and Arthur Frank, to use literary stories and narrative analysis as tools to increase our common understanding of practical medical issues (Charon, 2006; Frank, 1995).

# Oliver Sacks: From reluctance to the enrichment of patienthood

The British-American physician and neurology professor Oliver Sacks (1933–2015) mostly wrote case histories based on his clinical practice, including the acclaimed *The Man Who Mistook His Wife For a Hat* (1985). But in the illness narrative *A Leg to Stand On* (1984) Oliver Sacks also describes in detail his own personal and overwhelming experience of becoming a patient (Sacks, 1998).

In 1974, during a hiking trip to Norway, Oliver Sacks falls and severely injures tendons and nerves in the quadriceps of his left leg. After a short stay at a Norwegian dispensary he is transported to a British hospital for surgery followed by a period of rehabilitation. "Well, I have been a doctor for fifteen years. Now I will see what it



means to be patient" (p. 29), Sacks thinks to himself on arriving at the hospital. However, the stay turns out to be a more challenging experience than he had ever imagined. It takes time for Sacks to accept that he is now at the other end of the stethoscope, subject to the routines and regulations of the hospital. Tucked in a hospital bed he envisages the upcoming round as an explanatory act in an enigmatic drama. At the round he will finally have the opportunity to discuss with his doctor—between colleagues—the odd symptoms he experiences and the treatment options available. But when the hospital round has passed swift and efficient, without paying any particular attention to Sacks as a doctor (or even an individual), Sacks is left wretched and resigned. "I became all of a sudden desolate and deserted, and felt—for the first time, perhaps, since I had entered the hospital the essential aloneness of the patient" (p. 65).

What Sacks describes on being admitted to the hospital is a ritual ceremony following an invisible script, intended to convert him into a patient. In a series of depersonalising events he is deprived of his professional and personal identity and expected to subordinate himself to the implicit rules of the medical drama. However, Dr. Sacks' physical transformation to the patient role is considerably faster than his mental passage. The reason is partly his own resistance, but adding to the confusion are also the hospital staff, physicians and nurses, who do not know how to respond to this "doctorpatient." Oliver Sacks writes about the first encounter with his surgeon, Dr. Swan:



Both of us, in a sense, were forced to play roles—he the role of the All-knowing Specialist, I the role of the Knownothing Patient. And this was sharpened and made worse by my being, and being seen as, and partly acting as, his peer, so that neither of us really quite knew where we stood. (p. 81)

In her book Reconstructing Illness: Studies in Pathography (1999), Anne Hunsaker Hawkins shows that literary narratives of illness often dwell on a limited number of recurring themes; organisational metaphors that are shared by our cultural history and rooted in our human consciousness. One of these metaphors is the understanding of illness as a journey, and as an example of a literary narrative making use of the journey-myth, Hawkins specifically mentions Sacks' book A Leg to Stand On. Oliver Sacks describes his recovery as "a 'pilgrimage', a journey, in which one moved, if one moved, stage by stage, or by stations" (p. 132). For Sacks, it is mostly an inner journey through mental nooks and crannies to which he has never before had access. But it is also a physical journey into the hospital and further on to the convalescent home where he eventually learns how to walk again. Along this route, it turns out to be not primarily the medical actors and professional colleagues who guide him back to a complete identity. They do indeed provide the surgical procedure restoring the anatomy of his leg, but it is on the other side of the medical dichotomy that Sacks finds a



way to incorporate the experience of illness into his understanding of life.

Regarded as a mental journey, Sacks' story could be divided into a number of stages. Immediately after the accident he primarily relates to the incident as a medical event. His body is broken and it needs to be fixed. At this point, he takes little notice of the fact that his injury and the long period of convalescence ahead of him will also become a personal experience. Desperately, he clings to his accustomed medical perspective and only reluctantly conforms to the expected behaviour pattern of a patient. From the previously unknown perspective of the sickbed, he is slowly aware of a new kind of medical drama.

The posture, the passivity of the patient lasts as long as the doctor orders, and its end cannot be envisaged until the very moment of rising. And this moment cannot be anticipated, or even thought of, even hoped for. One cannot see, one cannot conceive, beyond the limits of one's bed. One's mentality becomes wholly that of the bed, or the grave. Until the actual moment of rising, it is as if one were never to arise: one is condemned (so one feels) to eternal prostration. (p. 107)

In the next stage of Sacks' mental journey he seems to accept the translocation from doctor to patient. But he also sets off on an active quest, for solace and strength beyond the truths of medicine. Guided by the Psalms in the Bible, the poetry of



John Donne, and the concertos of Mendelssohn, personal and healing perspectives of his illness experience appear. Perspectives he did not allow himself to see from his previous medical position. Music, poetry, and later the kinship of his fellow patients open up a mental passage between the biomedical and personal experiences and enable him to gradually regain a sense of control over body and soul (p. 85).

The music seemed passionately, won-derfully, quiveringly alive—and conveyed to me a sweet feeling of life. I felt, with the first bars of the music, a hope and an intimation that life would return to my leg—that 'it' would be stirred, and stir, with original movement, and recollect its forgotten motor melody. (p. 93)

Finally, when returning to his profession, Oliver Sacks once again assumes the position and external attributes of the doctor. But in his new medical identity Sacks has also incorporated the experiences from the sickbed. The doctor who returns to work is a different one. His illness has been overwhelming, but the role of the patient has not permanently deprived Sacks of the ability, nor of the desire, to serve as a doctor. On the contrary, he seems to be more motivated than ever before, spurred on by his newly acquired insights.

One must oneself *be* a patient ... one must enter both the solitude and the



community of patient-hood, to have any real idea of what being a patient *means*. (p. 142, emphasis in original)

From his new point of view Oliver Sacks is able to reach a deeper understanding of the subjective experience—illness—along with the biomedical approach—disease—which previously dominated his thinking. He has discovered, and to some extent bridged, the ontological gulf between the objectivity and subjectivity of modern medicine, and he is determined to carry this insight with him into his resumed and revitalised medical practice.

I would listen to my patients as never before—to their stammered half-articulate communications as they journeyed through a region I knew so well myself. (p. 168)

In many ways, the testimony of Oliver Sacks bears significant similarities to other autobiographical illness narratives by doctors from the 1980s. For example, the gastroenterologist's Robert Kravetz who, in the anthology *When Doctors Get Sick* (1987), describes his initial experience as a gastric ulcer patient.

Even now I am amazed at how tenaciously I clung to my role of physician when I had, in fact, become a patient, both acutely and critically ill. (Kravetz, 1987, p. 429)

And like Sacks, Robert Kravetz, on his return to medical practice, carries with him a less dualis-



tic and more holistic approach to his medical practice.

I am so much more aware of the 'art of medicine' and realize how the art has been almost lost to, and overshadowed by, the 'science of medicine' these days. (Kravetz 1987, p. 436)

# Franz Kafka: The coalescence of roles in the medical drama

From Sacks' autobiographical testimony, we move to Kafka's fictional short-story *A Country Doctor* (1919). Franz Kafka (1883–1924) wrote this story in the winter of 1916–1917, and it belongs to the minor group of stories he decided to publish during his lifetime. The plot is dreamy and full of surrealistic features. Still, in its depiction of a doctor's encounter with his patient, the setting is familiar, and it has been described as "an early (perhaps the first) modernist story about doctoring" (Manson, 2006, p. 297).

As the narrative opens, a senior physician is called for with great haste to a young man's sickbed, ten miles away. It is a snowy winter night and already in his courtyard the doctor confronts his first dilemma. The horse had "succumbed the night before to its over-exertions in this icy winter" (Kafka, 1992, p.156). By chance, two magnificent horses appear out of the doctor's pigsty, led by a previously unknown groom. The doctor departs, tormented by inner doubt realising, just as the horses take off, that the groom intends to violate his maid Rosa. Terrified, she has taken refuge in



the interior of the house, and as the howling of the wind fills his ears the doctor hears how "the door of my house burst and splintered under the groom's assault" (p. 157).

At the residence of the patient, expectations are high. The family place their faith in the doctor. Friends drop by to see the medical authority at work. But the doctor's visit is a failure. In his thoughts he is torn between his professional obligations towards the help-seeking patient and the moral responsibility towards his neglected maid. "How can I drag her out from under that groom, ten miles away from her, uncontrollable horses before my carriage?" (p. 158), the doctor ponders while twiddling with a pair of tweezers. Perhaps, partly due to his absent-mindedness, the doctor at first does not even manage to perform a proper examination. Then, when upon closer inspection, he discovers a large wound in the patient's side, he fails to provide any alleviation.

And this is where the story takes an unexpected turn. Because the moment the doctor proves unable to cure, his character merges with that of the patient. In a Kafkaesque scene of dreamlike absurdity, the family undress the doctor and place him naked in the bed, next to the patient.

There I stand stripped of my clothes, regarding the people calmly with my head bowed and my fingers in my beard. I am perfectly composed and superior to them all, and so I remain, though it doesn't help me, for now they



take me up by the head and the feet and carry me over to the bed. They lay me down against the wall, on the side of the wound. Then all leave the room; the door is closed; ... "You know", says a voice in my ear, "I have very little faith in you. You're just another one who's been wafted in from somewhere, you didn't get here on your own two feet. Instead of helping you're cramping me on my death-bed." (p. 160)

Like most of Kafka's stories, A Country Doctor invites various interpretations. There are reasons to believe that the story uses the real-life dilemma Kafka struggled with between 1916–1917 as a point of departure: the choice between devoting his life to writing, or to marriage with his fiancée Felice Bauer. From this interpretation, the forsaken home and neglected maid symbolises the desirable life as a married man. The doctor's medical work, on the other hand, represents what Kafka regarded as his true vocation, namely his writing (Ekbom, 2004). Throughout the short story, the physician struggles to choose between fulfilling his professional duty and retreating to his private responsibilities.

But from a medical perspective, it is far more reasonable to read *A Country Doctor* as a story about a general practitioner performing his tasks. What emerges from such a reading is a different story, the depiction of a doctor anguished by the discrepancy between the high levels of expectations of the lay people and his own sense of inadequacy. The family and the villagers expect the

doctor to perform miracles as a representative of modern medicine. "They have lost their old faith; the priest sits at home and picks his vestments to pieces, one by one; but the doctor is expected to accomplish everything with his sensitive surgical hand" (p. 159).

The features of doctor and patient in the first part of the story bear the hallmark of the classical medical drama: the doctor as a patriarch and upright authority, the patient as a fragile being lying in bed. The story thus follows the traditional plot, approaching its expected climax, as the doctor is to pronounce a diagnosis and provide an effective treatment. But when the physician fails to meet these expectations, he is bereft of his external attributes and placed next to the patient. Standardised dramaturgy breaks apart. Patient and doctor coalesce.

It is tempting to interpret these merging roles as a forced demotion of the doctor who has proven himself unable to cure his patient. In Kafka's short story there is equality between the powerless doctor and the "doctor as patient." In an article from 2006, Aaron Manson expresses this plight in the form of a question, but the answer seems, in fact, already given: "In the narrative the identities of patient and doctor merge. Is the doctor also a patient" (Manson, 2006, p. 302)?

In the new setting of the story, the doctor no longer understands his role. "What am I to do? Believe me, it isn't easy for me either" (p. 160), he grumbles, tucked down in his patient's deathbed. As he finally has to escape through an open win-

dow, his professional pride is demolished. "Never shall I reach home like this; my flourishing practice is done for" (p. 161), he laments while the horses start off with infinite slowness. The doctor has literally and symbolically been delegitimised and equated with the patient he has failed to cure. He has proven himself unworthy of the attributes of the doctor and been forced to accept the position of the patient in the medical drama. The doctor in the short story is, to quote Sander Gilman, "as much victim as is the patient ... wandering through the snow, unsure of his direction, of his calling, of his identity" (Gilman, 1995, p. 85).

# From classical scenarios towards a new approach

In the traditional medical drama of the twentieth century, the norm has been to present the doctor as an elevated expert and the patient as a compliant layman. In other words, a paternalistic and dichotomous approach, regarded as both natural and appropriate, has regulated the relationship between doctors and patients (McKevitt & Morgan, 1997b). In its turn, this approach has engendered stereotypes and a behavioural repertoire where doctors and patients have taken shape as two immiscible actors. However, to quote sociologist Erving Goffman "a performance is a delicate, fragile thing that can be shattered by very minor mishaps" (Goffman, 1959, p. 56). As the doctor becomes a patient, both caretakers and caregivers are bereft of their charted course of action and "the minute social system created and sustained by orderly social interaction becomes disorganised" (Goffman, 1959, p. 242).

In the world of fiction, the "doctor as patient" has most often been presented as a deviation from normality. This applies in the case of Bernard Shaw's The Doctor's Dilemma and Kafka's A Country Doctor, where the doctor in the sick bed is associated with qualities such as inadequacy and failure. It also applies to the first chapters of A Leg to Stand On, where the author, Oliver Sacks, by clinging to his medical perspective, denies himself access to a more profound understanding of affliction and recovery. In his ambitious compilation The Doctor in Literature (2006), Solomon Posen shows how fictitious doctors who suffer from illnesses are, in fact, seldom presented as patients. On the contrary, they are expected to handle their own ailments as professionally and rationally as they handle those of their patients. The doctor in fiction thus continues, despite illness, to present "the attitudes and behaviour patterns appropriate to his former calling. His medical training remains with him until he dies. Once a doctor, always a doctor" (Posen, 2006, p. 238).

Seen in this light, the initial unwillingness by Sacks to accept the role of the patient is not surprising. Eventually however, he becomes emancipated from his professionally assigned and restricted position in the medical drama. He then approaches a position where the objective and subjective perspectives as a doctor and a patient are able to co-exist. As historian Andrew Hull has argued, this strive towards a holistic understanding

of the clinical encounter was one of Sacks' major aspirations; he wanted "to create an 'intersubjective' medicine, in which the 'human' and the 'scientific' were integrated as equal partners" (Hull, 2013, p. 105).

As a portrait of an initially very disconcerting experience, *A Leg to Stand On* also illustrates what is equally visible in contemporary studies, based on questionnaires and interviews, of help-seeking behaviour among ill physicians (Kay, Mitchell, Clavarino & Doust, 2008). However, while these studies seek to structure *fragments* of an experience, Sacks' testimony provides us with a *fully-fledged* story. In that sense, the literary story that mediates a more nuanced experience than statistical analysis, no matter how scientific, is able to capture with similar lucidity.

The sick physician's experience of patienthood is complicated. After recovery, however, valuable lessons for an enriched clinical practice seem to have been learned. The Swiss psychiatrist Carl Gustav Jung (1875–1961) is said to have coined the term "the wounded healer" (Daneault, 2008). For Jung, a doctor's experience of illness was not only a potential threat, but also a valuable resource in his/her continued care of patients. A similar argument was presented as early as antiquity. As Plato writes about the social construction of his Utopia, in the œuvre *Republic*, the characteristics of a good doctor are also touched upon. And Plato's words are considerably more hopeful than those by George Bernard Shaw from the introducing quote of this article.

In order for doctors to attain perfect skill, they must not only have learnt their trade. In addition, from childhood onwards, they should have come into contact with as many bodies as they possibly could, in the worst condition they could find; moreover, they themselves should have contracted every single disease there is, and should be constitutionally rather unhealthy. I mean, it's not their bodies they use to treat other people's bodies, of course; if that were the case, it would be out of the question for their bodies to be bad or to get into a bad state. No, it's their minds they use to treat bodies. (Plato, 1993, p. 109)

Illness among doctors as an opportunity for *experience-based medicine* in the deepest personal meaning of the word.

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### A Disease of Dignity

James K. A. Stevens

From my old report cards I know I overslept and missed the bus fifty-eight times in my junior and senior years of high school. It got to where I bought five alarm clocks, including one old-timey one with twin bells and the little hammer between them, because Amazon advertised it as exceptionally loud. One Amazon review said the clock woke the reviewer's 90-year-old grandfather, who had hearing problems. Another reviewer wrote, "This alarm will wake the dead!"

It never woke me, though. Sometimes I'd wake up two or three hours after my five alarm clocks had gone off. I'd reset my alarms, realize I was beyond late for school, then hate myself as much as I'd ever hated anyone. Then I'd sneak into my closet and go back to sleep. I'd lay out my blankets and pillows on the closet floor, curl up my body, knees to my chest, and close the closet door. I'd doze off two feet under my jackets' sleeves and jeans' legs, as comfortable as I could be. When my mother came home from working the graveyard shift, she'd think I was gone. Then I'd wake up at



whatever time in the afternoon, after my mother had already gone to sleep herself.

I was always tired. When I did make it to school, I'd fall asleep, head on desk, in most classes. I'd stumble off the school bus steps around 3:00 P.M., drop onto the bed or couch or floor, and wake up around eight or nine or ten the next morning. I sucked down coffee, a taste I hated. I downed energy drinks and energy shots until I shook. Then I bought pure caffeine on the internet to mix into everything I drank. But I still slept entire days away.

I chalked it up to my workload, at first. I had taken ten Advanced Placement (AP) classes and played two sports. My grades had put me at the top of my class in sophomore year, though that class rank plummeted by the end of the next. I had always been academically successful, moving up classes, skipping a grade. Even with my sleeping problems, I would graduate high school at sixteen, so part of me figured daily exhaustion was par for this course.

My voice lowered and became monotone, and my gait slowed. I lost weight, because I ate only once every two or three days, and I wore the same clothes, dusty gray thermals with fat wool socks, for weeks without showering. No one who noticed, no teacher, classmate nor coach, neither my mother nor any other family member, ever asked me, "Are you alright?". No one inquired about my health or suggested I see a doctor. Instead, I heard jokes, rumors, and accusations, even from my mother, that I must be skipping school on purpose.



Maybe I just wanted to lounge around all day, suggested my AP Chemistry teacher.

Or maybe I was on drugs. I mentioned to my AP Biology teacher how tired I was. He scoffed, "You're clearly smoking a lot of weed."

The vice-principal called me down to her office to discuss my absences. I explained that I felt tired all the time. She said, "Look, I know it's hard to get up in the morning, but we're all tired."

When I confided my exhaustion to my mother, she said, "You're just lazy."

Little bits of me still showed up in standardized tests, even though my grades tanked. I could cut through a two-hour-long AP test, even if I couldn't function for a seven-hour school day. They gave me awards: National Merit Scholar, AP Scholar with Distinction. I had 99th percentile SAT scores. Some schools mailed me offers of full scholarships, despite my grades. I was approached by faraway schools—Florida State, UC San Diego— and I received a generous offer with a foreign travel stipend and a free iPad from the University of Arizona.

I accepted their offer. Coming from chillier New Jersey, I figured the sizzling Tucson sun would spark me awake. But at the U of A, my sleep trouble persisted. I overslept entire days of classes. Then I started to wake up nervous. In my dorm room I had little breakdowns, feelings like bones snapping, when I shot up every morning to check the clock. Was it 6:00 a.m., 8:00 a.m., 2:00 p.m.? Would I trudge to class, exhausted enough to cry, or silently hate myself for waking up too



late? If I saw something like 6:15 on the clock, my brain zapped itself. I refocused my eyes to see whether it was A.M. or P.M. I couldn't trust what day's half I woke up in.

Again I showered as if they were rationing water. I bought a burger maybe once every other day as my only food. My classmates, high-achievers in the U of A's Honors College, gave me funny looks and passive-aggressive insults. Angel from down the hall twisted his face and spoke slowly to me, to mock how distant I was, how detached, stupid, or high I must have seemed. After my second semester, the university rescinded my scholarship. I failed my favorite class, a senior-level honors psychology seminar that my adviser had recommended me for as a freshman. My professor wrote me a thousand-word email, describing how "unmotivated" I seemed, how my "priorities seemed to be elsewhere". After I'd had three poor semesters and a 10-day trip to the psychiatric ward, my mother bought me a plane ticket back to New Jersey.

For the next three years, I bounced from therapist to therapist for depression and anxiety. These people, who were always old, foreign to me, and soft-spoken, laid it out: it's problem with serotonin, obviously, or dopamine. No one mentioned sleeping too much as its own disease, but they were right about the mood disorders. I had gotten into cutting my arm with razors and, after I came back from Arizona, attempted suicide, hanging myself with a belt until I lost consciousness. Then the belt gave and I woke up, as usual, in a daze.



Every therapist I met said it must be due to my depression. If I could patch my mental state, then I would smooth over my sleeping problems. However, even in spots where my depression improved, when I felt motivated enough to work or return to Arizona, I still averaged almost sixteen hours a day asleep.

In January 2014, my primary physician referred me to a new psychiatrist. However, I was certain my problems originated in my sleep, rather than my mental outlook. I had been reading about different kinds of brain problems, including injuries that could lead to sleeping all the time. So I called my physician's office and finagled a referral to another specialist, a neurologist. After two appointments, this neurologist, recommended three sleep studies. One of these was a polysomnography, an overnight sleep study. My mother drove me to the sleep lab. A technician fitted me with electrodes and a finger pulse monitor, and ran through what must have been his usual "It might be hard to sleep in a new place" speech. I zonked out in their bed before I knew it.

Most adults spend about twenty percent of their sleep in the REM stage, the deepest stage, where most dreaming occurs. The healthy range is seventeen to twenty-three percent. If you wake up during REM sleep and need more, you might enter "REM rebound" next time, where you fall into REM sleep faster than normal. REM rebound is evidence of how biologically important REM sleep is; it's necessary for cognitive function. My polysomnogram, the charted result of my



polysomnography, told me I only spent 4.8 percent of my sleep in the REM stage. My body delayed entering REM sleep for more than three hours after I had fallen asleep. The neurologist suggested that my sleep failed to restore me, as if I were constantly sleep deprived even after being out for twelve or more hours. The neurologist and the testing physician who ran the polysomnography both agreed with a diagnosis of a rare sleep disorder called "idiopathic hypersomnia".

Hypersomnia is sleeping too much, the opposite of insomnia, and idiopathic means there is no known cause. Idiopathic hypersomnia has an estimated prevalence of one in twenty thousand. Remission occurs in about ten to fifteen percent of cases. The hypersomnia remained regardless of the medications I was taking. I had no history of head injury or anything else that might have caused excessive sleeping. There was some strange neurology, something interfering with my sleep. But there was nothing we could find as a cause.

There's no FDA-approved treatment, so my physicians and I went through off-label medications by the boatload. They prescribed antidepressants: citalopram, escitalopram, bupropion. Then there were stimulants: modafinil, armodafinil, and Adderall. I didn't feel anything from the first two, and the Adderall gave me headaches that felt like little buzzings, or beads of sand whishing around my brain. There was lorazepam, because I also had panic attacks, and levothyroxine, to increase my levels of thyroid hormone, even though my tested levels were within normal range. I contin-



ued to see therapists for depression and anxiety, trying to fight the two-fronted battle. I wore down my mental gears more, fighting sleep problems and mood problems, with therapists, psychiatrists, and neurologists. I wanted all the tools, weapons, and resources I could gather. There's still, on top of my dresser, a sheet of sleep hygiene "tips and tricks", describing how I should force myself to sleep at certain times, wake up at the same time every morning, and not use my bed for anything other than sleeping or sex. But this was advice for a person whose problem originated in behavior, not neurology. I could sleep at almost any time, anywhere, in cars, or on park benches like a bum. It had been a joke in school that I could sleep standing up, just leaning on walls in the hallway. Waking up at the same time every morning was impossible as far as I could tell, because I had always slept through every alarm clock. My mother even put ice cubes down my shirt once to wake me up. She told me later that I had screamed and knocked the ice out my shirt, and that I screamed so loudly that she would never wake me up again, not for anything. She'd rather just let me sleep.

She still wanted me to be active, however. My single mother had grown up poor and angry in the ghetto, in Atlantic City, and had fended for herself for most of her life. When I asked her for food money, she told me, "Don't come asking me for money. I'm not giving you anything other than a room, and you should be grateful I'm giving you that at all." So I needed to work for my own



money, pay my bills, buy my food. For my part, I also ached to work. I saw being able to work fulltime as a measure of functionality. If I could get up, shower, get dressed, and work for eight hours a day, without passing out the second I got home, then I would be healthy enough to return to university studies. From 2013 to 2016, I took on and lost more jobs than I can remember. I worked for two Walmarts, five pizzerias, a shoe store, a flower shop, a bookstore, a gutter repair contractor, a flag football league, and more. I lost all of these jobs, except one, due to oversleeping. I overslept some shifts entirely. The shoe store manager, who lived nearby, offered to give me a ride to work. On the first day he stopped by, I slept until noon and woke up with five missed calls and seven text messages. He had pulled up to the house, honked his horn, knocked, called, and texted me on my unmuted, full-volume phone. I snoozed through the whole thing.

I tried to mitigate my shame by being obsessive about the time I spent asleep. I recorded every hour I spend in any activity on an Excel spreadsheet. I recorded the times I fell asleep and woke up, in an effort to keep them consistent. I wrote down times on sticky notes, and later typed them in Excel. I recorded the times I spent working or looking for work, reading and studying, going to the gym, and so on. Sleep dominated, with an average of 13.9 hours a day spent asleep. After three months with no change, I slipped into another stay-at-home depression.



My mother berated me, in some way she thought was galvanizing, about how "worthless" and "useless" I was becoming. When that effort failed, she kicked me out the house, an attempt at "tough love", to motivate me into keeping a job. I spent four months on friends' couches, then the county homeless shelter, then the psych ward again, before my mother took me back in. I was crippled, non-functional. I spun into a mental cycle of fear, embarrassment, anger, and self-loathing over both my inability to do anything and the abandonment I felt from people I had believed were my support. My mother, I figured, only kept me because she was obliged. She gave me a room, because she couldn't have people calling her a terrible person if I wound up homeless again.

Then my hypersomnia went away. I don't have an explanation of how it improved. I didn't change my diet or start taking a miracle plant extract. I just started sleeping less.

I remember the first week I spent sleeping fewer than ten hours every day. It was the last week of April, 2017. On May 2, I slept nine hours, a cool nine, like a normal person, not twelve or sixteen or twenty. Then on May 3, I slept eight hours. When I woke up, I felt fine, not tired, not dazed, not in a weird stupor like before, where I'd be falling over if I managed to wake up with this little sleep. That afternoon, I realized something was up, and I started jotting down my hours again.



It was just sleep, but that week I was on a roll. Every night gave me a restful eight or nine hours, without an alarm, without any drugs. And when I did set an alarm, it actually woke me. Then a week of normal sleep spun into a month. That summer, I found a job working at a local tennis center, attending to the courts and teaching tennis (I had played the sport competitively). I was late to work a few times, but I never had a problem with staying awake or with oversleeping entire days.

My improved sleep transformed my health. I took care of the normal things, showered, and ate at regular times. I gained healthy weight. I stopped having panic attacks. My hypersomnia diminished spontaneously. It was a downright miracle.

Now I'm 23, picking up my life where I dropped it at 19. My social network died: No one has kept in touch with me from high school or from Arizona. My frozen academic life is thawing out through community college classes.

My old depression has left, but now a new one comes when I think of how many people judged me as being stupid or lazy or drugged out. If I had not been my own advocate, and insisted on seeing a neurologist who brought up sleep studies, I have little doubt I would have ended my life. The anguish of being teased at school and reviled by my mother, the lack of support I needed at such a vulnerable time was closer to killing me than hypersomnia ever had. And though I'm still getting along, working and studying, something has left me. The people closest to me accused me of being a lazy, stupid person who probably smokes a lot of



weed, with the same blind, mobbing ostracism as if they had accused me of committing a robbery. Because of that, I lost a trust in people in the same manner as a person wrongfully convicted of a crime. I might sleep well now, but I think I'd feel most rested if I could ever find people to rebuild that trust.

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### For the Old Man on His Death Bed

### Anne Rose

An ode to old Stubbornness
And ladders climbed near 90
To fix the unfixable dawn
To patch what couldn't be
Patched, all those Decrees
Laid down like roof tiles
All those Curses, Blessings,
Invectives, Injunctions, Invocations,
All that money you got when
You bartered away your children for ...
A Big House that still leaks
Sorrow all over the neighbour's lawn
A Cadillac and marble steps
Where do those steps lead
You now, is it up?

An ode to an old man's Rightness
And to a night nurse
Even more Stubborn than you.
Eternal Lightness of the Mature Mind
Each of your siblings disagreeing while Right
Each one Right enough to proceed you to
Wherever you may be going
Do they have hedges or hedge funds



Can you take it with you or can you Once again defy death by Marinating in good wine? Is good wine better than the IV line Dripping out what's left of the Running out and down of Time?

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### How to Befriend a Cadaver

Maggie Hulbert

First, remove the skin. It's easiest to pull it off in strips, peeling off layers of hair and fat like peeling an orange. It will be simultaneously gruesome and tedious. Your hands will cramp and your mouth will taste like disinfectant, but show no weakness. Your cadaver is testing you, waiting for you to succumb to the fragility of being alive and having senses. Go home that night and have a shower, but know the smell will not leave you for four months. This cadaver is yours for the term: male, aged 57.

Next, cut the ribs. Don't eat beforehand, because the smell of bone on saw will be shockingly familiar, smoky and rich, with an undertone of rotting sweetness. You will avoid eating meat for weeks. Rivers of embalming fluid will flow from the chest, forming small pools in the body bag. Rolls of paper towel and armfuls of rags will not staunch the flow. You have angered your cadaver, exposing it to the fluorescent-lit world. Give up, and work with wet sleeves. You have a heart to find.

The chest will take several weeks. The heart is blanketed in a layer of fat so thick and pink it re-



sembles muscle, and you will cut into it under constant threat of severing arteries. Your cadaver will remain indifferent as you unwittingly remove the entirety of the main coronary blood supply. During teaching sessions on this subject, you will sheepishly bring forward a plastic model, admitting the ignorance to which your cadaver bears witness. You have lost to your cadaver, and should learn to be more humble. There is so much you don't know.

During the lung dissection, you will consult an old anatomy textbook flecked with dried pieces of flesh from its lifetime of use in the cadaver lab. Your cadaver will reward you with pulmonary vessels shaped exactly like the pictures; you are learning. Admire how the lungs fit snugly into the chest, and for a second, let yourself feel a strange pride in the size of your cadaver's heart. Think about what once made that heart race, and consider how similar that heart must be to your own. Try to entertain these thoughts for only a moment, but be warned that they will pervade. During the evenings you spend at home with your head on your partner's chest, you will no longer hear his heartbeats as reassuring. Instead, each one will be a reminder that the only thing between life and death is the absence of this sound.

The abdominal dissection will reveal your cadaver's deepest secret, disclosed only to you and the surgeons who left those stitches in the abdominal wall. The tumors clustered around the vessels, intestines, and liver will be so large in number and size that they make identifying structures near impossible. The sticker on the table will impassively remind you that



the cause of death was pancreatic cancer. You will be the only one surprised by what you see.

With every structure found to be obscured by tumours, you will silently curse your luck and look on with jealousy at the others at their tables, easily locating gallbladders in the cadavers of those who died of heart disease. Each of these thoughts are accompanied by guilt. Who are you to judge what qualifies as a good death? The hours you spend painstakingly separating metastases will be your penance for not appreciating the gift your cadaver has given you. When you come to the pancreas itself, look for a tortured and enlarged organ, riddled with growths and partially eroding into the main abdominal artery. Appreciate that your cadaver could not survive this, and it was these very tumors that took your cadaver's life. If you feel overwhelmed by the burden of mortality at this point, take a break and go outside. Call your father, who is your cadaver's stated age. Tell him you love him, and that everything is fine, but will he please stop smoking? Then go back inside.

Leave those tumors intact and recognize what is really meant by the caution "treat cadavers with respect." Your cadaver has fought and lost more than you ever have. To remove those tumors would do a disservice to this battle, even if your students will gripe about missed learning opportunities and seek out other cadavers to learn from. Highlight the mass on the pancreas and use this chance to remind students of the mortality rates of pancreatic cancer. Privately, think about how you would feel if your death was equated to a statisti-



cal fact, but suppress the urge to apologize to your cadaver out loud.

Leave the face for last, to ensure you have sufficient skill to remove facial skin and tissue without damaging the delicate web of vessels and nerves that runs right underneath them. You will not think you have this skill, but do it anyway. Feeling nervous as you dissect the face is entirely natural. Remove the plastic wrap and cloth to reveal a kind, albeit sunken, face. Observe the strong jawline and cloudy blue eyes, and don't be surprised if you feel stubble when you put your hand against the chin. Do this final dissection with care, and note how easy it is to be alone with your cadaver. The violent colors of muscle and blood will have softened, and you may forget how many hours vou have been in the lab. If you find a tattoo behind the ear, smudged little initials of someone's name, let yourself imagine that special someone putting their arms around your cadaver's neck. Appreciate, finally, that your cadaver has not always been yours, but more importantly, has not always been a cadaver. You might feel overwhelmed by the realization that your cadaver was a person, whose heart once beat as yours does now, who decided to give their body so you could learn. You will not be able to comprehend what went into making this decision, but it is a good exercise to try. Carry this realization into the remainder of your dissection, and do not be embarrassed to feel concern for what will happen to your cadaver as the term comes to an end.



On your last day, look closely at all the wounds you have inflicted, and give silent thanks to your cadaver for absorbing them without complaint. Wrap the hands and feet with damp cloth to prevent the structures from drying out in storage, and smooth disinfectant on all the muscles you have exposed. Acknowledge how much you have learned, and recognize that the cost of this education was a life. You are now finished. If you feel a pang of sadness as you zip up the body bag for the final time, you will know that you have befriended a cadaver.

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# The Perfume of the Dying

### Kim O'Connell

Throughout her life, my Aunt Peggy wore perfume like an accessory—a different one for every day, and plenty of it. Her scents came out of the Avon catalog and had exotic names like *Ariane* and *Foxfire*, florals and musks that hung on my clothes long after she'd left a room. The perfume decanters on her vanity were like a row of hothouse flowers, pink and amber and white, full-sized and "purse-sized." Even the mini ones they threw in the shopping bag as extras were on display. As a girl, I loved to sample them, usually two or three at a time.

The long-forgotten memory of the bottles comes back to me as I sit on the edge of a hospital bed in Maryland, squeezing Aunt Peggy's hand. It is a cold night in February, and my aunt is as white and gray as the hospital walls. She is in the advanced stages of metastasized lung cancer and going into septic shock. She can no longer speak, but she turns her head in my direction, her mouth slightly open. I caress her opalescent arms and try to talk in soothing tones, knowing that each breath takes us closer to the inevitable. Hers, weak



and slow, and mine, way too fast. I will myself to stay calm, so I inhale. All around us is a dense, sweet smell, the telltale scent of the dying.

A lifelong smoker, Aunt Peggy wore perfume in part to mask the smell of cigarette smoke, that other smell that I always associated with her. Unlike her wanton taste in perfume, she was a loyalist when it came to cigarettes; only Virginia Slim menthols, famous for the "You've Come a Long Way, Baby" slogan, would do. My aunt had started smoking as a teenager in the 1960s, back when it seemed sexy and cool. She was definitely sexy and cool, but the cigarettes only enhanced those qualities. They didn't create them. In one of my favorite photos of her from that time, she is wearing pedal pushers and patent leather heels, her hair done up in a bouffant and her lips painted bright red, with a cigarette held aloft in her elegant, manicured hand.

By the 1980s, my aunt was a middle-aged, child-less divorcée with a two-pack-a-day habit. Accordingly, her voice had taken on a gravelly timbre that somehow matched her brassy, fun demeanor. My parents had divorced by then, with my father awarded sole custody. Straining under a high-powered government job, he invited my aunt—his only sibling—to help take care of my younger brother and me, offering her a room in our house, a weekly stipend, and a built-in family. In her free time, she sold encyclopedias door-to-door. She became fast friends with the local Avon lady, and they would light up together in my father's kitchen, poring over makeup and perfume samples.



We made room for both my aunt's perfume bottles and her cigarettes in our lives. My aunt loved to dance around the house singing songs. The Everly Brothers' "Bye Bye Love" was one of her favourites. She would sing, "Bye bye love ... bye bye happiness ...," flinging ash on our carpet. She once burned my forearm with a cigarette as she swung me around, horrifying my father. I rubbed some cold water on it. What was a little burn when there was dancing to be done?

My aunt was awfully partisan when it came to my brother and me. When my dad wasn't looking, she would sneak me cans of soda and bags of Doritos. Later, when I lost my virginity, she was the first person I told. Her eyes widened, but when I begged her not to tell my father, she agreed. She was not my mother; she was my accomplice. When I met the man who would become my husband, she bought me my wedding dress. When I walked down the aisle, I could smell her perfume before I could actually see her, and when I did, she had tears in her eyes.

A few years ago, when we found my father dead of a heart attack on his living room floor, my aunt helped make all the arrangements, negotiating with the funeral home like the tough-cookie saleswoman she was. She smoked a lot of cigarettes then.

There was a time in my know-it-all twenties when I tried to get her to quit. In fact, I was downright judgmental about her smoking habit, sending her preachy cards and emails. I asked her to smoke outside my house, even when it was unbearably



hot or cold. I wrinkled up my nose when she gave me a birthday gift and a smoky odor wafted up from the tissue paper. I wasn't always very nice. In those moments, I told myself that I had her best interests at heart. Now I realize that I really only had mine. I wanted her to stay with me, and for our lives to remain as they were, full of perfume and dancing. She knew before I did that that was impossible.

As the years went on, Aunt Peggy's voice grew hoarser; her breathing raspy and strained. She began to have bouts of coughing and confusion. After she'd fainted getting out of bed one morning, she finally visited the doctor, who confirmed our worst fears—Stage 4 lung cancer, with a poor prognosis. "That's what I get for fifty years of smoking," Aunt Peggy said matter-of-factly, without tears or self-recrimination. She began chemotherapy. When her hair fell out, she bought pert wigs ("I have brown hair again!") and spritzed cologne on the diaphanous scarves she tied around her head. She wore her trademark red lipstick to her chemo appointments. She lived one day at a time, the way we all ought to live and almost never do. She kept smoking.

One day, a brain scan revealed a large mass. The oncologist immediately ordered a round of radiation, but I heard the tone of last resort in her voice. Eventually, our options ran out.

And so I sit in this hospital room, surrounded by the perfume of the dying. I have heard that our bodies have myriad ways of informing us when organs are shutting down, and this peculiar scent is



one of them. It has been described on medical forums as a "sickly, fruity smell" and is often associated with lung and other cancers. Physicians going back to Hippocrates have made the link between disease and certain odours, and so none of the medical staff attending to my aunt seem concerned about the strange smell. What's surprising is that I'm not bothered either. It reminds me of hiking through apple orchards in Pennsylvania in the fall, when they are thick with the scent of fallen apples, often split open by opportunistic animals and left to ferment in the sun.

My aunt falls into a sleep from which I know she will never wake. I notice her purse, sticking out of a half-open drawer. I lift it out, carefully, and unzip it quietly. The purse contains a single, small bottle of perfume—Sung for Women. I take off the cap and inhale, catching citrus and floral notes and musky undertones. I desperately want to spray the perfume on my aunt's thin wrists. I long to paint her pale lips red and offer her a cigarette. I wish she would dance and sing. Bye bye love ... bye bye happiness ....

Instead, I take her translucent hand in mine. I try to thank her without actually saying the words, because that feels too final, but I believe she knows. Her breath slows. I inhale the strange perfume, this last, intimate expression of her humanity. The scent lingers long after she's gone, and in this one vital, glorious way, nothing has changed.

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# Recipe for Refracgtory Status Migrainous

# Jennifer Wolkin

- 1. Place two screws in my right temple.
- 2. Embed forcefully until flush with flesh.
- 3. Take pliers—hinge them on the bridge of my nose.
- 4. Squeeze for five minutes every five minutes.
- 5. Use a paring knife to poke both eyes.
- 6. Twist.
- 7. Put three fluorescent lights directly in the center of my gaze.
- 8. Put another two in each periphery.
- 9. Use x-ray vision to watch my brain dilate wide like an expecting cervix.
- 10. Bring me to a dark dwelling.
- 11. Adorn me with: heat pad around neck, ice pack on frontalis, pillow between legs.
- 12. Listen to me mutter "shoot me" as the pain throbs.
- 13. Ignore me. I want to live, just not like this.
- 14. Bring me an abortive med (at least as a Band-Aid).
- 15. Read to me in rare asymptomatic intervals. Rajiv's work is my preference.
- 16. Tell me you love me, even if loving my invisible illness isn't easy.
- 17. Repeat steps 1-17.

Jen Wolkin is a health and neuro psychologist. She has just started her MFA in creative writing and literary translation at Queens College. Email: Jenniferwolkinphd @gmail.com



# Philip Larkin's *Myxomatosis* and the Problem of Empathy

Michael D. Shulman

### Myxomatosis

Caught in the center of a soundless field
While hot inexplicable hours go by
What trap is this? Where were its teeth concealed?
You seem to ask.
I make a sharp reply,
Then clean my stick. I'm glad I can't explain
Just in what jaws you were to suppurate:
You may have thought things would come right again
If you could only keep quite still and wait.

Larkin, 1954

Philip Larkin's reputation as the "best-loved British poet" (Booth, 2014, p. 1) of the twentieth century has faced opposing forces of late. He is revered for giving a poetic voice to the gloom felt by many people with the collapse of ancient religious and social props but has also been the target of virulent rebuke for his misogyny, racism, and

his "unrelenting atheism and pessimism" (Vendler, 2014, p.20), especially as revealed in his posthumously published letters. "Myxomatosis" is an early poem, written in 1954 when Larkin was 31 years old. It displays the more amenable side of Larkin's complex personality, and its sentiments conform to the elements of his biography that are easiest to embrace. It also touches on themes that are of great interest to anyone who believes that the practice of medicine might absorb lessons of value from the poetic sensibility.

In middle-age, Larkin wrote a never-published autobiographical fragment in which he recalled the "dominant emotions" of his childhood to be "overwhelmingly, fear and boredom" (Motion, 1993, p. 13). The atmosphere of the parental home he remembered as both "drab" and "intimidating." One result of these fraught human connections seems to have been a deep regard for animals, with a special place reserved for the most hapless specimens. When Larkin began to publish novels and poems, ultimately achieving considerable distinction, his perplexity over relationships and his concern for animal suffering were preserved in equal measure. It is likely that this concern for neglected or damaged animals hid an element of perceived psychological kinship. Larkin never married or had children. Bald and bespectacled, some might have considered him plain (among them, the poetry critic Helen Vendler (2014), who writes of his "lack of good looks" (p. 20) as if it were a biographical detail as fixable as his birthplace. Unsurprisingly, then, when animals entered his poems, it was

on a note of commiseration. "The Mower," for example, was written after a lethal encounter between Larkin's lawn mower and a hedgehog he had been supporting with table scraps. "[Philip] came in from the garden howling," Monica Jones, his long-time (and long- suffering) lover recalled (Motion, 1993, p. 475). In the poem "Ape Experiment Room," Larkin characterized vivisection with a palpable shudder as "putting questions to flesh" (Larkin, 1988, p. 160).

Rabbits were an especially privileged species in Larkin's universe. He admired Beatrix Potter, the author of the Peter Rabbit books, and referred to the devoted Monica as Bun (short for Bunny Rabbit), addressing scores of letters to her in what his biographer calls a "private language of rabbittenderness" (Motion, 1993, p. 459). Growing up in the English Midlands, Larkin would have been accustomed to sightings of feral rabbits, whose number circa 1950 has been put at 100 million (Sheail, 1971, p. n202). Despite their cuddly appeal to children, in rural England rabbits were widely regarded as pests. Myxomatosis was written in response to an effort to exterminate the rabbit population wholesale by exposing it to the myxoma virus, a pathogen previously unknown in Europe. The ensuing controversy is of interest for the light it throws on the constituencies then asserting themselves—farmers, furriers, sportsmen, lovers of animals and lovers of meat (meat in that post-war period was still rationed) all in contention. But for admirers of Larkin's verse, the controversy is also of interest. It led, in *Myxomatosis*, to what is perhaps an inadvertent exercise in soul-baring

that can be better understood with a bit of historical and biological background.

In 1896, a Uruguayan research laboratory discovered that a mysterious febrile contagion had gripped a dozen or so rabbits previously imported from Europe, killing all of them within weeks (Kerr, 2012). The course of the illness was grimly predictable. Tumors of the skin and underlying connective tissue (called myxomas, after the Greek word for mucus), with an ugly predilection for the head and genitals, were its earliest manifestation. Within days, the flesh became swollen and empurpled. The skin bulged grotesquely, as if the rabbits were being misshapenly inflated with air. Fever, anorexia, and lethargy then followed, leaving the animals stupefied and inert. These symptoms were accompanied by a purulent ocular discharge and marked engorgement of the eyelids. The animals were then helpless. Opportunistic bacterial infections—typically pneumonia—mercifully took root as the end approached. When death did come and it came in every instance—the animals were almost always blind.

Later experiments established several key facts. The source of the rabbits' illness was shown to be a pox virus (a Leporipoxvirus of the Poxviridae family) usually transmitted by blood-sucking insects such as fleas and mosquitos (Villafuerte et al., 2017). The myxoma virus, like the serial murderer in a generic thriller, was found to choose its victims fastidiously, striking down only one species of rabbit—Oryctolagus cuniculus—and an occasional hare. Squirrels, ferrets, and guinea pigs were unaf-

fected (Chaproniere & Andrewes, 1957). More intriguingly, myxomatosis could not be induced in human subjects. When study volunteers were injected with tissue from moribund rabbits, they emerged unscathed (Hobbs, 1928). Seeing one's volunteers in robust good health after being injected with a virulent pathogen naturally closes the book on one publishable line of research. It is the kind of result an ambitious investigator greets with mixed feelings.

The story then leaps forward to 1952, when Paul Delille, a retired physician living in France, weary of the despoliation of his carefully tended cultivars, injected a suspension of myxovirus into a rabbit and released it onto his estate. European rabbits, having had no prior exposure to the virus, lacked any resistance to it, and mortality was 100 percent (Fenner & Marshall, 1957). Less than a year later, on the other side of the English Channel, a few dead rabbits were discovered on a farm in Kent. The infection then spread exponentially, abetted by "rabbit destruction squads" composed of British farmers who viewed wild rabbits as a pestilential swarm of Biblical proportions. Opposing the farmers were "mercy squads" that roamed the countryside putting stricken rabbits out of their misery. The sight of dying rabbits starving, disfigured, and blind—grew familiar to tender-hearted British citizens who, after a childhood spent in the company of Peter Rabbit, viewed with alarm the disappearance of his reallife cousins from a large swath of rural England (Bartrip, 2008).

Larkin's Myxomatosis memorializes the poet's encounter with one dying rabbit. Like a medical practitioner caring for a close family member, the poet vacillates between professional detachment and horrified identification with the object of his ministrations. The affectless title of the poem could serve as the chapter heading of a textbook. But prodded by the grisly image before him, the emotional current in the poet rises. He imagines in fact shares—the experience of being caught in an invisible snare. The interminable hours, "hot" and "inexplicable," refer to the animal's fever. But they could apply as well to the fury and consternation of the poet as his nature walk is transformed into a Dantean passage through a limbo of crippled innocents.

The word "suppurate," with its Latinate and clinical associations, signals another poetic *volte-face*—a return to the anaesthetizing distance available to the poet at the start. In this moment of restored equanimity, the poet delivers his bloody *coup de grâce*: "I make a sharp reply, then clean my stick." The language is spare—no mention of the unavoidable spattering—and by allowing the reader to conjure his own image, the effect is multiplied, disquietingly so.

The decisive mindset that brings the stick down upon the stricken rabbit does not last very long, however. The poem closes by restoring the pathos of a sickened creature in torment—the torment not of physical pain, but of anticipated extinction. It is the same anguish evoked so brilliantly in Larkin's "Aubade," where it is also pro-

voked by the specter of death, "the anesthetic from which none come round" (Larkin, 2003, p. 190). Caught in extremis, Larkin's rabbit is revealed to be a mid-twentieth century Christian of lapsed faith, aspiring to salvation, but knowing that merely to "keep quite still and wait" is hopeless. Things will "come right again" to be sure. And it will be in the form of a final, annihilating blow from above.

That Larkin should look upon a wild rabbit in its death throes as a fellow sufferer of existential dread illustrates the distinction, so often blurred. between empathy and sympathy, two responses that are not only divergent but can lead to opposite results. Sympathy is closely allied to compassion and kindness. It calls forth feelings of tenderness and the wish to protect its object from harm. Empathy is, in contrast, an involuntary, inward-turning process that recreates in the observer the suffering witnessed in others. Yale psychologist Paul Bloom defines empathy as a capacity "to experience the world as you think someone else does" (Bloom, 2017, p. 16). This closely follows the great primatologist Frans de Waal, who called empathy "the ability to be affected by the state of another ... creature" (De Waal, 2005, p. 184). Nothing in either definition leads one a priori to believe that empathy results in a charitable or moral impulse. Indeed, empathy with members of our own tribe may encourage murderous resentment for anyone outside it. But if empathy is ultimately an internal matter—if unlike sympathy, it is an unsought state of private distress—there is a possible outcome

that is even worse than violence against tribal enemies. Empathy might actually give rise to violence against the creature provoking it.

Once that possibility is raised, *Myxomatosis* can be seen in a new light, one that produces an off-putting sense that the dying rabbit of the poem is oddly dispensable. If it is true that the poem is offered as a protest against animal abuse, it is also true that it is offered without the faintest breath of tenderness. "I clean my stick" cannot strike the rabbit-lover as a terribly fitting epitaph. But then Larkin, while he was sometimes maudlin, was not a very tender-hearted man. A poet who fills his letters with expressions of contempt for women and inferior races, and yet recoils howling when his mower strikes a hedgehog, has perhaps confused love of animals with love that finds its true object closer to home.

It is precisely in that confusion—that intermingling of unworthy motives with charitable ones—that the problem with empathy lies, for unlike sympathy, empathy is inseparable from self-regard. *Myxomatosis* is a very good poem, and it is terribly moving in its way, but who does not perceive that it is first and last a poem about Larkin? The dying rabbit is a morbid figment, its corpse a simulacrum constructed from the poet's dread of illness and death. This is because the essential nature of empathy is to turn our thoughts from the suffering of others to the torment it produces in ourselves. But if this is true of empathy, what hazard is created for the empathic medical professional who must absorb the horror of human affliction daily?

How much of the case for mercy killing, for example, disguises a wish to dispatch the patient and put an end to a misery that must otherwise be shared? And what is true in medicine is true elsewhere. If empathy turns the suffering of others into a source of personal anguish, how tempting to seek relief, as the poet does, by extinguishing the source. And perceiving clearly that temptation, how tragically but singularly human seem the all-too-familiar stories, both in art and in life, of men and women who kill the thing they love.

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### Semmelweis to Szent Rókus

Daniel W. Galef

I've seen mankind made new by death and birth,
Yet remain whole, as if we're one great man
Composed of men, like Hobbes' Leviathan.
This hospital—Vienna—or the Earth—
Is as one body. We're its meat and mind,
The corpuscles that form its brawn and bone,
Those who well serve their function left alone,
The rogues dissolved; their husks are left behind.
Is being left the cost of being right?
Like those who burned affirming Earth revolved
You turned on me, and, seeing me a threat,
Consigned me to this social phagocyte
Where—Rókus knows—I won't accede, and yet
I'll be absorbed before I'll be absolved.

Daniel Galef's series Imaginary Sonnets is inspired by the 1888 collection of the same title by Eugene Lee-Hamilton. Email: daniel.galef@ mail.mcgill.ca



### Inheritance

Judith O'Connell Hoyer

It's nothing you get from walking in the woods. No asking Google *Why me?* A change in the DNA from one generation to the next is what the oncologist said to me.

The tumor is gone now.

Two permanent ink spots on my backside
an empty double port on my chest, above my heart
and a silver line that runs
from my navel to the top of my pubic bone things that were left to me.

I'm reading "Great Expectations" for a second time. Yesterday I bought two pairs of heels instead of one. I'm not sending Christmas cards this year.

Judy's chapbook *Bits* and *Pieces Set Aside* had been nominated for a Massachusetts Book Award. Email: Judithhoyer675
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# Writing His Own Ending

Rebecca E. MacDonell-Yilmaz

I met Lon a week after he had been told that he would die soon. After a year of troubling symptoms—slowing gait, stooping posture, slurring and thickening of his speech—he had finally grown too sleepy and confused for his family to do anything but bring him to the emergency room. Positivepressure ventilation courtesy of Bilevel Positive Airway Pressure (BiPAP) helped flush the carbon dioxide from his system and cleared his sensorium just in time for him to learn his diagnosis: Amyotrophic Lateral Sclerosis, an unfortunate diagnosis by any standards. But rather than broadcasting its intentions by first weakening the limbs, then progressively overtaking Lon's ability to speak, swallow, and breathe, this less common bulbar subtype had robbed him of these functions straightaway.

A feeding tube was inserted with what might have been knee-jerk consent, still startled as he was to come face to face with his mortality just past the age of seventy. However, Lon adamantly refused a tracheostomy, even as he grew to require BiPAP for an increasing number of hours each day. Given the choice between ventilator dependence and transfer to inpatient hospice with removal of the BiPAP and impending death, he chose the latter.

By the time our paths crossed during my hospice and palliative care fellowship, Lon was barely able to speak due to the mask constantly present on his face, in addition to the weakening of his vocal cords. Yet I could imagine his voice as strong and deep. I could see him holding court in a boardroom or at the head of a dinner table, wearing a blazer and loosened tie, even though I had seen him only in a hospital gown. "Harris tweed," he wrote on a dry erase board by way of greeting when one of my colleagues entered his room wearing exactly that.

Lon had little patience for the process of dying; while he clearly cherished time with his wife and adult children, who set up camp in his room and stocked every corner with snacks, beverages, laptops, even a printer, he asked me every day how much time he had left.

And every day I told him that I didn't know.

Lon, it turned out, was able to tolerate aroundthe-clock BiPAP surprisingly well. When the skin on the bridge of his nose grew raw, he tried a different mask that relieved the pressure to his nose and also allowed his glasses to perch on his face so that he could read notes from friends and peruse the daily paper. And so Lon simply went on living.

I learned from the first time I entered his room that Lon could communicate only via messages written on dry erase boards. Meniere's disease had damaged his hearing even before the ALS wreaked havoc on his central nerves and impaired his speech. He grew irritated when others conversed around him without transcribing their discussions so that he might follow and take part. The day that I met him, I scrawled a feeble-seeming "Hi" on the board that his family handed me, followed by my name. "I'm going to be your doctor," I wrote, then turned to him for a cue, unsure just how we might proceed.

I needn't have worried; Lon took it from there. We grew acquainted. I learned tidbits of his Irish Catholic upbringing and found that we shared a love of poetry. He distributed copies of a salty limerick to each member of the staff. It might have been crude, but for the fact that each was adorned with a personalized message of thanks. Mine read: "Doc, thanks for always being honest."

It truly was the only thing I could offer. He had little in the way of emotional or spiritual symptoms, other than an honest curiosity about what the future would hold. I talked and wrote through the pathophysiology of the disease with Lon and his family, explaining as clearly as I could that his muscles, especially his diaphragm, would continue to weaken, impeding ventilation, and that carbon dioxide would once again build up in his brain. It would happen despite the use of BiPAP, I told them, though I couldn't predict how quickly. The only way to truly keep it at bay would be to initiate invasive ventilation via tracheostomy, which Lon adamantly refused.

So we focused on the things that he could do and enjoy. Once he learned that taking nutrition through his feeding tube would be unlikely to alter the course of his disease, he had no desire to use it. With no significant appetite, and understanding his risk of aspiration, Lon chose instead to take sips of the beverages whose tastes brought him some joy. Coffee: as hot as possible. Smoothies: always mango, always cold. He took visits from family and friends, and during long "talks" with his wife and children, expressed sentiments that they captured by taking photographs of the dry erase boards, preserving his words written in his own hand.

Though he usually greeted me with a list of prepared questions, on some days he seemed to have nothing further to discuss. "Go take care of someone who needs you, Doc," he wrote one morning with a smile, waving me away. "I'm fine."

Had he been asked a year or even a month before we met how he would like to spend his final days, I doubt that Lon would have described sitting in bed tethered to a BiPAP machine, communicating with his family by scrawling his every thought and need with a dry erase marker. It hardly sounds like what most of us would call a good death.

But, then, what is a good death? I confess that I entered my fellowship training with the belief that a good death required a code status of DNR/DNI, cessation of all cure-directed treatments, and a sole focus on management of pain and spiritual and emotional symptoms.

I can now appreciate the naïveté—and, frankly, the paternalism—of my earlier beliefs. A good

death, I have learned, is one in which the circumstances adhere as closely as possible to the patient's wishes and goals at that time, whatever they might be. While not all wishes can be brought to fruition, the actions and interventions taken by a family and medical team can and should be informed by the patient's desires, even if the ultimate outcome cannot match what the patient hopes for. I cared for one young boy who declined precipitously after his cancer metastasized and though his parents would have preferred to have him at home, they felt unable to manage the caregiving that would have entailed. The team outfitted his hospital room to mimic the comforts of home, replacing the plain hospital linens with plush bedding patterned with his favorite cartoon characters and adding posters, matching pajamas, and a few toys. Another patient chose to continue receiving intensive inpatient chemotherapy for her widespread disease but put a DNR/DNI order in place because she wanted to avoid transfer to the ICU and invasive, potentially painful, interventions. By contrast, many of my patients have continued to seek cureoriented therapies and have maintained a status of "full code" even in the face of illnesses that cannot be cured. If a patient truly understands that there is a slim likelihood of recovery, but still prioritizes extending his or her life by every possible minute and knowing that every available intervention has been tried, that, too, can be a good death.

These goals can shift as a disease progresses, as symptoms change, or as patients' understandings of, or feelings about, their illnesses evolve. The chance to help patients identify what is most important to them and to engage as a team in developing a plan of care consistent with these wishes—even if they are the polar opposite of what I value and would choose for myself—is one of the distinct honors of working in hospice and palliative care. My goal remains to help provide, to the best of my ability, a good death for every patient. Only now I recognize that a good death can take many forms.

The day eventually arrived when Lon's handwriting began to grow sloppy. In his list of daily questions, inquiries appeared that didn't make sense and that he couldn't explain further when one of us drew a question mark in the margins.

"Is it the carbon dioxide?" his children asked guardedly and I nodded. They whispered, but he seemed unperturbed by the conversation taking place around him. This was the progression we had expected to see, only we hadn't known when it would start and still had no idea how long it would take. We had talked, for a time, about discharging him from the inpatient facility to receive hospice care at home or in a nursing facility, but it was becoming clear that Lon's time was growing short.

Gradually, Lon grew less and less alert and spent more of each day asleep. His pain didn't increase, but he, who had once—even in these dire circumstances—been a robust and notable presence, began to wilt away. He used the dry erase boards less, and was not as irritable when people had conversations without translating their spoken words into writing. And while his family contin-

ued to grieve, they also felt great relief that the inpatient hospice facility was where he would stay.

Lon passed away in the early morning hours of St. Patrick's Day with his family by his side. When I arrived later that morning, the funeral home had already collected his remains and his family had packed away all of his belongings and the accoutrements that had made his room feel so much like a home. In their wake, they left a note of gratitude thanking us for the care that Lon had received. It was written, most fittingly, on a dry erase board.

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#### The Professor

Room 433

#### Cheryl Hindrichs

If I should die in this sterile bed think not this of me, me paging listlessly through one of those magazines that eddy as flotsam here. Let me be found not with an expired glossy slippery, over my cavernous chest a surreal bust and brilliant white teeth arched, grinning or, perhaps seeming clenched as if she knew of the skeleton stretched beneath her. Instead, when the monotone drops from beating, beating, ceases. Find me with Beckett or Barnes, Whitman or Woolf. Rather than Judy pronouncing justice, let there be silence in this corner of a hospital wing, or, if you must, let a fly buzz.

Judy, of course, is ubiquitous elbowing around corners, there when I've dozed and the nurses come through. Perhaps others are comforted by the theme with variation? Black robes and white jackets. Red halter tops and blue smocks.

We each have our nightstands of sorts, practical—space for a cup with bendable straw, the vomit bag like a coiled snake, but also a bit of space left over, and here we place our totems. This is how we know them. the others, like planets, or skiffs, that come and go the orbit of the ward. A vase of tulips, color yellow, for the woman who hums the ice cream truck song, incessantly. A stuffed cat with stripes and sleepy eyes, for a man who hugs a pillow all day and night. A bowl with fruit-shaped candies like faded gems, for the woman who dials hospitality several times a day, "no calls?"

And, finally, and most improbably the nightstand with the fly swatter, Although in all my time here I have seen neither fly, nor cockroach. Once I thought I saw a white cabbage moth dancing at the window pane, as, often in the garden, I recall

that ghost dancing its own melody over the hollyhocks. But it was a trick of the light or my eyes. Not even a spider of the smallest sort, not even a fruit fly! And here where fruit is hauled in, basket piled, waxed, enormous, impermeable, impossible as the cut-glass candies. Surely some fruit fly might crouch in the paper grass? They must have a man just for flies, an emperor of insects, escorting them out, under Judy's righteous intonation. Could a swatter keep her at bay? Or slap at solemn pronouncements, a thwap at death.

On my table, a book. A young man, once my student, placed it there delicately, in the empty space. Inscribed probably. But I haven't lifted the cover. Despite the long empty hours, the high windows. I haven't sought the release of the "M," gigantic, wonderful, trumpeting across the first page. To do so now would mean to return to look, merely look at, the passionate imagined intimacy that was Him (behind the "M") and me. It would mean a return, not to the field itself

to wrestle and embrace, as once I tumbled headlong, full of passionate intensity, experience multiplied by the voice of my own Virgil who led me, deeper, always deeper. Is he, too, on this other side? Does he look, merely? I believe he's still alive, his children professors themselves now perhaps. If I were to raise a feeler, test the air, as once I did, the thread, invisible, unreal, would be still, limp, let fall. But I've done my mourning already, waited out in exile, without cunning or guile. The green cover with its harp has proven useful for impressing the doctors, the nurses, of course, see through it, and, so, it stays shut.

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### On Grieving

#### Simon Perchik

These dead again and again

follow behind as the goodbyes that never leave home, overgrown

till they gag in what passes for dirt asking for a blanket or snow —what you spit on the ground

is the melt, making room inside where there was none before and each breath further away

though you can hear your teeth grinding down the word for we when there was nothing else.

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You lift a small stone on top

till the smoke turns black become a chimney-sweep scraping the dust with flowers cut in half, were still alive helping you remember

though once your hand is empty it opens the way these dead were gathered from dirt

each year higher, are listening for rising air and mourners used to so many steps :her grave

knows how lovingly the ashes fell cling to the ground as nights side by side still counting the grass

by twos though you come here for work, ask for work with rags and dried-up brushes.

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They still cling to your fingers

as pieces :this cemetery is all that's left from an empty shell

that became the Earth, patched with wooden tools and tears to lower the ground—by themselves

take this dirt by the hand already an endless breeze warmed by your soft blouse

unbuttoned each Spring to show what emptiness looks like from inside where you point as if step by step sharp picks are cracking open your gravestone not yet amber or gravel.

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Though it's late for the sun

once you add sand the extra weight lets it take hold

where the chimney could be would cover your hands with ashes when there's no smoke left

—not yet built and already you hear the fists banging from inside to show what the door looked like

once it's shut and the next morning no longer comes by, was melted down for the sea now crammed between this shore

and the other—you dig and you dig for salt, want to keep the water fresh close to the schoolroom bell you hear

—no! a heel-click is what and barefoot you grasp for shoes the children will never outgrow

that wait till nothing moves not their feet, not the laces, one by one pulled out by the hand, heavier and heavier.

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Not with linen—stone works better

lasts the way you dead still gather as if the sun not that long ago

had a twin who died in the night became this hill kept warm for you, your mothers, fathers

and the brightness that was left to tell them what's going on to close your eyes, that that's

why you're here, move closer hear who still loves you wants you step by step to stay.

Simon Perchik is an attorney whose poems have appeared in *Partisan Review, Forge, Poetry, Osiris, The New Yorker,* and elsewhere. For more information, please visit www.simonperchik.com. Email: simon@hamptons.com



# The Lunger in the Attic / The Dead Abandoned at Crest Sanatorium, 1935

#### Lisa Alexander Baron

#### The Lunger in the Attic

Everyone gets jumpy at the sound of my hollow coughs, and they are afraid to touch me. Here in this room level with the tree tops and the songs of too many birds, I can still hear my brothers and sisters below me. But now they are fragmented voices, and I have to try to imagine their gestures as they talk. Drifting in and out of sleep all night, I wait for the startle of a red rose—or even a carnation on the breakfast tray my sister slides through the window they built for me.

#### The Dead Abandoned at Crest Sanatorium, 1935

(to be read in the round by different voices)

Patients, nurses, doctors, gardeners, cooks, potters, weavers, and all visitors gone. The wind is the only rattle-like cough now drifting through the broken, airy windows and the hollow halls of the Sanatorium. We were dropped off. Abandoned— To take the air. to try the cure. We fought, but we did not heal. We were never picked up. Now we are just a row of stones Untouched as we were untouched in life. Even a single lily dangerous, too dangerous to lay at our feet.

Lisa Alexander Baron's latest poetry collection, While She Poses, was prompted by visual art. She is a professor from Philadelphia who teaches advocacy in writing and speech to health professionals. Email: baronlisaalex@gmail.com



#### **Mortality Knocks**

Pamela Walker

I have been thinking about mortality, reflecting on the causes of death in my family. There were tragedies: My grandfather died of a "leaky heart" at the beginning of the Great Depression when my mother was only 10, and my younger brother was killed in a car accident when he was 19. There was stupidity: My paternal grandmother died of a stroke at 70 because she refused to take blood pressure medicine. "That ol' Stoykavitch," she said of her doctor, "he just wants your money." The norm for our family of hearty Midwest stock, however, is to live long and healthy lives into our late eighties while keeping our wits about us.

My father and grandfather succumbed at the Mayo Clinic during or after surgery for aortic aneurysms. My mother died of sepsis and pneumonia, though imaging had revealed arteriosclerosis in the small intestine. She could no longer digest food. In other words, we die of old age. The coronary system gives out. The pulmonary system becomes fragile. The body no longer fights off bacteria as it did. In your family, perhaps the killer

is cancer, diabetes, or Alzheimer's. What I am coming to terms with is that all of these death options share inflammation as their cause.

You know inflammation. Let's say you're walking at a good clip when you trip on an uneven sidewalk. If you fall and scrape your knee, the point of contact will become inflamed. It will grow painful and red, swollen, and perhaps hot as blood rushes to the injured site to repair tissue. It's no surprise that the word derives from the Latin *inflammo*, "I ignite." This is inflammation at its best, intense but short term, the immune system fighting harmful stimuli, such as damaged cells and bacteria, and beginning the healing process.

Inflammation at its worst is chronic, resulting when the immune system attacks healthy tissue, mistaking it for harmful pathogens. This type of inflammation is at the heart of a wide variety of serious disorders, including health conditions that end in "itis" (arthritis, colitis, dermatitis, sinusitis) (Aronson, 2009) as well as AD/HD, migraines, thyroid issues, depression, and even autism (Khansari, Shakiba & Mahmoudi, 2009). In addition, inflammation begets inflammation. Women with inflammatory autoimmune disorders like Crohn's and celiac disease are at greater risk of giving birth to children with autism (Atladóttir, Pederson, Thorsen, Mortensen, Deleuran, Eaton & Parner, 2009).

While it's a pity that inflammation is the culprit behind visible signs of aging (Giacamoni, 2018), I accept crepe-like skin and the loss of youthful beauty. What confounds me is that my medical history has led inevitably to a health crisis I did not recognize for years. It appears to have begun a few years after we relocated to Southern California. I was walking with my neighbor Sue around a duck pond when my body grew warm, my eyes began to smart and itchiness crept down my body from scalp to ears, neck, and arms. I am a scratcher with lifelong eczema and adult onset allergies to the usual flora, fauna, mold, and dust. Naturally, I scratched. I am a world-class scratcher. Then as now, I scratch mercilessly - angry red ridges rise on the back of my hands. My legs are pocked with scabs. I scratch because it hurts to itch.

That day I felt a mysterious prickling at my lips. Back in Sue's car, I was shocked to see that my face had transformed into a mask of welts; it was a hideous face with bulbous lips, one I had never before encountered. My internist diagnosed hives and prescribed adrenalin injection pens, in the event my throat closed shut, which it never did. As long as we lived in California, these swelling episodes occurred at the beach, the park, a hot tub in Santa Barbara, and once in the middle of a four-hour class I was teaching. I didn't cancel class; I reasoned the result was unsightly but benign, a mere inconvenience. I hid my bulging eyes behind sunglasses.

Our first year back in New York, retired in the city of our dreams, I was allergy free, enjoying a whirlwind of all the exercise I love, but had no time for when I was working - walking, swimming, lifting weights, riding my bike along the Hudson, and meeting friends for yoga. Smugly, I thought New York was the answer, as it always has been

for my husband and me. The allergens that had made me miserable in California did not exist back East, a notion I gladly subscribed to until one autumn day, following a reunion with my childhood friend Donna at a Chelsea restaurant. After lunch, we walked the High Line, where I ran my hand through tall grasses that shimmered in the hot sun.

Donna and I bid good-bye on 23rd Street and I was standing on the subway platform when my breathing grew ragged. I had not had an asthma attack in years. It had been so long, in fact, that I could not remember when I had last renewed the prescription for the inhaler I retrieved from my purse. I attempted to breathe in on the pump, but I wheezed with whistling breath to no avail. By the time I reached home, my face had exploded to alien proportions and I was heaving lunch on our apartment door as I fumbled for the keys. I thought the restaurant had served me rancid mayo, and that asthma with hives was some new intrigue in a sensitive autoimmune system ignited when I ran my hand through the High Line grasses. My internist recorded "allergy-induced asthma attack" and wrote prescriptions for a more powerful inhaler and new adrenalin injectors. I felt fortified.

Over the next six months, the attacks gained in frequency and severity. It happened in yoga, and the doctor said to stop doing yoga in an old Soho factory. It happened at the gym, and I let my membership lapse. It happened indoors and out on cold days and hot. The pulmonologist was perplexed and unhelpful until I took a picture of my bloated

eyes and crooked mouth at George Washington University Hospital, when my husband and I were on a weekend get-away. We had walked about two miles from our hotel in Georgetown and had just entered the park between the Lincoln and Vietnam Memorials when I lost my air. I am always astonished by the rapidity with which attacks arrive. On one side of the street, I was walking whole and on the other side, I was doubled over on a bench near a concession stand, clammy and suffocating.

"This is not asthma!" the doctor exclaimed, referring me to an allergist who took one look at my data collected over seven episodes and congratulated himself on diagnosing my problem in a split second: exercise-induced anaphylaxis, a rare disorder with no cure. Symptoms usually follow vigorous activity, though mild exertion can trigger attacks in cascading levels of severity: warmth, itching, and nausea precede angioedema, what my doctors mistook for hives. Although hives are also a symptom of an allergic reactions, they appear on the surface of the skin. Angioedema is swelling of mucous membranes below the skin. Anaphylactic shock occurs if soft tissue in the throat and larvnx swells, narrowing airways and producing shortness of breath similar to acute asthma. Within minutes, blood pressure falls, heart rate accelerates, and cardiovascular collapse will occur without urgent medical treatment that includes adrenalin (Lewis, Lieberman, Treadwell & Erffmeyer, 1981).

"You have to slow down," the allergist said.

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I am nine years old, on the exam table in Dr. Gibbs's office overlooking the Mississippi River and the bridge to Illinois. I have come with my mother for a checkup because I am recovering from rheumatic fever, a rare but potentially deadly disease that typically develops after untreated group A streptococcal infections, such as tonsillitis and scarlet fever. Dr. Gibbs surmised that I had contracted scarlet fever but my parents mistook the rash for eczema. Rheumatic fever would rob me of three consecutive winters. I could only watch as my younger brother learned to ice skate, etching figure eights frontwards and back, gliding around the rink at great speeds, right boot lithely crossing left, hands clasped behind his back like drawings in our Hans Christian Andersen book.

Rheumatic fever is an autoimmune disorder. The body produces antibodies to fight strep, but for unknown reasons, they attack the body's own tissues instead, inflaming the heart, blood vessels, and joints. Complications of rheumatic fever killed Bobby Darin in 1973. Like me, he suffered three bouts, beginning at the age of eight, but he was 12 years older, way sicker, and not as well cared for as I. The fact that rheumatic fever develops in only a few cases with an identical precipitating infection suggests differences in genetic susceptibility (Acheson, 1965).

One summer my mother fell ill with rheumatic fever and was hospitalized. My brothers and I, ages four, five, and six, were cared for by a stranger in the Manor, a development of dull yellow cinder-block rentals erected during the War to

house an influx of workers at the Army Ammunition Plant. Because the duplexes were identical, it was easy to get lost, escaping the park, where the local ruffians fought us for the swings. The babysitter served canned peas, while our mother served the bright green frozen variety, only recently available.

Summer had just begun when my nine-year-old self was looking at the river and thinking how I would learn to slalom with my brothers. We'd jump the wake with knees to chest like Wisconsin Dell performers. I felt cured; my joints weren't sore. Still, the doctor said I was not so well. I could not ski or ride my bike. I had to walk, not run, even when my brothers peeled off a block ahead, and I had to nap. I hated naps; I hated sleep altogether. I would never learn to slalom. The doctor prescribed a pill to slow me down. In the car, tears streaked my sweaty face. "I don't want tranquilizers!"

"They're not tranquillizers, just sedatives," Mom offered. I knew I could not believe her.

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Despite childhood illness, I have lived an incredibly healthy life. I rarely have a cold or flu. I rank in the bottom 20 percent of women my age for the likelihood of developing arteriosclerosis. I do have a mitral valve murmur, which indicates scarring on the left side of the heart, but it requires no treatment. I still ride a racer bike, sleek and light, designed for quick handling and optimal power with

drop handlebars that put you in a more aerodynamic position and clipless pedals, which anchor your feet so that you are literally one with your cycle. Recently, monthly shots of an antibody that decreases incidences of hives and severe asthma have been successful in ameliorating my angioedema and anaphylaxia. I have ridden my bike for the first time in 18 months. I cannot ride far, just far enough to feel free of illness and fear. I still have attacks, but for nine months, they haven't affected my breathing.

This inflammatory crisis did not begin in California. Inflammation has been my constant companion, active at times and in remission at others, a distant whisper easily ignored. I sought to outrun it as long as I could through the practice of perpetual motion, but you cannot outrun yourself.

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## Of Unknown Origin

Ali M. Tahvildari

The beads of sweat collect at the notch below your sallow neck your jaundiced skin salted, where nothing can thrive your feeble body probed again and again to understand perhaps for our sake more than yours what we can only call a fever of unknown origin.

I stand across from you uneasily leaning against the cracked crimson paint of the windowsill each hiding behind our shields: your thin parchment gown and my flimsy white coat starched for some semblance of control over this fear of unknown origin.

Afraid that you'll see my confidence lacking, that you'll see me as a confidence man, dismayed that with all our advances we can remain so uncertain. I brush the coarse strands of your auburn wig from your shuttered eyes—a favor of unknown origin.

There lie the roses that you will never smell the apple that you will never taste and there in the corner float the red balloons that you might have liked to release to the sky in a fervor of unknown origin.

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# Transplanted / At the American Museum of Visionary Art: *The Gateway*

Marjorie Maddox

#### Transplanted

Though they'd never met, the man with the dead man's heart inside him dreamed his donor's face, limbs, lungs; sung in his sleep the dead man's favorite song in the deep baritone voice that wasn't his own but his, the one not known or seen or heard, except in night's deep cradle of sleep, this stranger's metronome of a heart humming behind ribs that no longer felt like his-beautiful fence for an organ lifted from someone else's afterlife. Even waking, the newold man and his heart now know nothing of old boundaries, the ones composed by the living. Instead, in bright, silent daylight, he takes his first, tentative beat toward love.



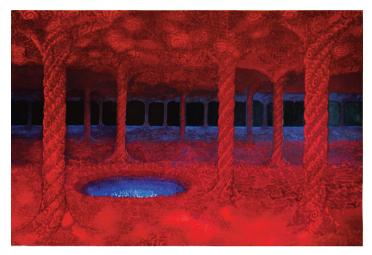
Heart Speaks, Is Spoken For by Karen Elias (USA). Contemporary

# At the American Museum of Visionary Art: *The Gateway*

— Artist Antar Mikosz

Even with 3D glasses, all you can see are trees swaying in a breeze of blood beside a swampy pond murky with nightmares. A rapist lingers somewhere in the periphery. I, too, hear him breathing, his damaged heart heaving inside your terror that clings to thick vein-like trunks patterned with geometric tastebud recipients of bitterness—the ones in all our bloody pumps. This is the way of perception. Fear steers me toward the portal of your forest, but all I can see

is the inside of my father's heart where, from a deep hole, his donor's car careens into scream that bubbles up now from the pond of your words into my father's aorta, pulsing a rhythm of red that remembers foggy dreams painted by a young man detouring an icy life into accident or gift, this gateway mysterious in its pathway of give and take, in the perception of breath we can not swallow, the visions we see daily vibrating between now and here, between lovely, dark, and deep.



*The Gateway* by Antar Mikosz. Courtesy of American Visionary Art Museum.

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