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Provisional Interruption: Living, Writing, and Teaching through End of Life Care

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Provisional Interruption: Living, Writing, and Teaching through End of Life Care

Cover Page Footnote

For my parents.

“Perpetual Interruption”: Living, Writing, and Teaching through End-of-Life Care

*We're safe,
For the moment.
Saved.
For the moment.
--James Murphy*

“In the beginning is an interruption,” Arthur Frank writes. “Disease interrupts a life, and illness then means living with perpetual interruption.”¹ In the end is also an interruption. Disease ends a life and means an end to perpetual interruption. News of my father entering hospice care came via that most contemporary of perpetual interruptions: a text message notification on my laptop. I actually saw it arrive, a message from my brother. The bubble popped into the upper right-hand corner of my screen: “We will need to decide between hospice or a feeding tube.” I saw it arrive, and then, before I could click on it, watched it recede beyond the margin of the screen. I saw it because I was looking at my laptop. I was looking at my laptop because I was in class, standing at a podium, preparing to lead a discussion. Fifteen students were arranged in a half-circle, busily writing in response to Frank’s concept of perpetual interruption. My training as a literary scholar did not allow the irony to escape me. For the previous eight months, Dad had been shuffled between different memory care facilities and the older adult behavior unit of a nearby hospital, Alzheimer’s disease eroding his ability to reason, to walk, to talk, and, finally, to chew and swallow without aspirating his food. To my siblings and I there was no question: hospice care. An end to interruptions.

Such interruptions—via text, email, or phone call, from nurses, doctors, home health-aids, neighbors, and one another—had been part of our lives for longer than eight months. For me, it had been one year, eight months, and two weeks since I got news of our mother’s impending CT scan. News that it was happening, though not the results (interruption: cholangiocarcinoma—three tumors, all in her liver, metastasized from her bile duct, one the size of a grapefruit). It was, “Schroedinger’s cat scan,” I joked at the time. More irony: I made that joke while participating in a Telling/Writing exercise led by Rita Charon at the Project Narrative Summer Institute at Ohio State University. That workshop had been my first, sustained introduction to the field of literature and medicine, as well as to the writings of Arthur Frank, among others. The following two years brought a series of interruptions: visits to cancer centers, emergency rooms, and memory care facilities as well as meetings with oncologists, hospice nurses, and funeral directors.

As both of my parents entered the end stages of their lives, I was bringing my understanding of health humanities and narrative medicine into my classrooms for the first time.² Living, teaching, and writing through my parents' illnesses and deaths collapsed my roles as scholar, teacher, and caregiver, thereby casting into stark relief what Ann Jurecic has called the, "falsely absolute divide between everyday experience and critical engagement."³ Jurecic's divide—between a living self and a scholarly self, or between a teaching self and a living self, or among all three selves (scholar, teacher, individual)—arises, she continues, from, "a position of distance and privilege."⁴ We can, for instance, discuss Frank's theory of narrative, or apply it to a work in hand only when we have sufficient remove from such an experience.

However, this critical act relies on a subject/object distinction, and such a distinction marks the scholarly reader as separate from the popular, casual, or naïve reader. To identify too strongly with a work prevents one from exercising the proper objectivity. Jurecic's primary argument accounts for how and why a mode of literary studies informed by what has come to be called, following Paul Ricoeur, "suspicious reading," fails to understand the function and popularity of illness narratives. Essential as it may be to the scholarly exercise, Jurecic notes, critical distance does not, "serve literary and cultural criticism well as a tool for understanding life's precariousness."⁵

Therefore, another form of reading is required of scholars. Jurecic turns to what Eve Sedgwick has called "reparative reading." According to Sedgwick, "to read from a reparative position is to surrender the knowing, anxious paranoid determination that no horror, however apparently unthinkable, shall ever come to the reader *as new*; to a reparatively positioned reader, it can seem realistic and necessary to experience surprise."⁶ Such surprises, according to Sedgwick can, of course, be horrific. But the reparative position is also attuned to other possibilities: "Hope, often a fracturing, even a traumatic thing to experience, is among the energies by which the reparatively positioned reader tries to organize the fragments and part-objects she encounters or creates."⁷ Such reading, is, Jurecic elaborates, "interested in a kind of learning that seeks meaningful ways to live with both not-knowing and the prospect of not being."⁸ Accounts of the experience of illness, an especially those which directly confront the end-of-life, it would seem, can best be approached via a reparative mode of reading.

Narrative medicine, in the terms of Rita Charon, functions precisely to better understand, or better hold together, something like the precariousness which characterizes the position of "not-knowing" and "the prospect of not being," or at least our understanding thereof. In *Narrative Medicine* Charon describes her clinical work in part as a form of reading. "What my patients paid me to do," she writes, "was to listen expertly and attentively to extraordinary stories—told in words, gestures, tracings, images, laboratory test results, and changes in the body—and to cohere all these stories into something that made provisional sense, enough sense, that is, on which to act."⁹ Charon's mode of reading here moves beyond Sedgwick

and Jurecic's reparative, offering something different, which I am calling a provisional reading.

This provisional sense, it seems, is the power of what she elsewhere calls the "clinical imagination."¹⁰ I think such a stance extends beyond the purview of the clinician, and informs how we all, in Jurecic's terms, "understand life's precariousness." Disease interrupts because it calls to consciousness that precariousness. And interruption demands provisionality. That is, the ability to hold understanding and judgment just enough in order to act, but loosely enough to recognize multiple possible meanings at once. A provisional position affords one the willingness to hold a truth in suspension – to hold it lightly, knowing change will come, knowing interruption is inevitable, and yet one still needs to act: to teach, to write, and to live. Therefore, in what follows I consider how provisionality plays a role in my practice as a literary scholar, as a writer, as a teacher, and as a care-giver. Specifically, I aim to consider how, over the last two years of my parents' lives, I turned to the provisional as a way to hold together, if only for isolated moments, different stories, different domains of knowledge, and different versions of myself.

In a classroom in Queens on a warm Wednesday night last March, I had no real choice but to do so. I paused for a moment after seeing the text from my brother. I had known Dad was not well. He had not been since Mom had passed away the previous August. But the reality of his impending death was new. I felt the new information physically: my stomach dropped and the room swam in my vision. For a moment I considered simply cancelling the rest of class, with or without explanation. I chose not to for reasons professional (a lack of tenure), pedagogical (an already interrupted semester), and personal (a romantic nod to my father's forty-plus-year teaching career). As I stepped away from the podium I also knew that I would have to hold two truths in suspension (Dad is dying/I have to teach this class) and find a way to act. I would have to find a provisional position in that moment, a position that reading, teaching, and living the health humanities has facilitated.

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Soon after Mom was diagnosed with her tumors, I felt like I knew precisely how to act. In the late summer of 2016, my dad, my sister, and I accompanied Mom to her first appointment with her medical oncologist. I carried a notebook and a pencil, as well as a copy of Margaret Edson's *W;t*, a play about a professor of seventeenth-century English poetry suffering through treatment for ovarian cancer which I would be teaching for the first time later that fall.¹¹ Dad also brought some unintentionally ironic reading material for the waiting room: the most recent issue of *The Economist*, a magazine he used in his American History and AP Government courses, and that, as his dementia progressed since retirement, had become a talisman of security whenever he left the house. The cover article that week addressed medical advancements in slowing senescence, detailing how soon not just

new hips or new knees, but new livers and new neurons will be marshaled to combat the, “disposable soma.”¹² On the cover, the article’s title – “Cheating Death” – framed an image of an hourglass. Dad elbowed me and pointed with a wry smile, his only open acknowledgement of where we were and why we were there. I snapped a picture with my phone and texted our two brothers, both anxiously awaiting our report in their respective east coast cities.

As we met with the medical oncologist I wrote furiously, filling the pages of my notebook with sloppy notes that I would later transcribe in an email to my siblings. I recorded specifics about Mom’s diagnosis, the size and location of her tumors, the nature, duration, and efficacy of her treatment options, the names of the chemo drugs, their response rates, the chemo schedule and likely side effects, the location of the hospital hair salon. I asked questions, as did my sister, about the possibility of other forms of treatment, about immuno-therapy, about radiation, about a second opinion, about what we would know and when. We fought anxiety with information. Mom was mostly quiet. Her medical oncologist, a warm, smiling woman roughly my age, had begun by asking her if she understood why she was there. In my notes I observed that the physician had read her Charon. The doctor began the consultation by giving Mom space to tell her story. “What do you understand about why you’re here today?” she asked. To which Mom responded, “Well, I guess because I have some cancer.”

But I knew it was not that simple. There were layers of meaning to be uncovered. So, I filled my notebook with notes, that day and the next. I wrote exhaustive emails to my three siblings and in-laws. I broke Mom’s illness down by category headings (“Diagnosis,” “Treatment Logistics,” “Food and Drink,” “Knowing How She Feels,” “Odds and Ends”), each including bulleted sub-points and PDF attachments. I brought my training as a critical reader and scholar to this project. This was how I would act. This, I remember feeling, was how I would control. I had no illusions about the prognosis—I accepted that Mom would die from this—but I knew that death could be managed. These emails strive desperately to map a future with no surprises and thereby to anticipate the interruption. I felt if I knew the story, if I kept diligent notes and synthesized those notes, if I could just read it right, then we could, if not cheat death, at least frustrate it for a little while.

Much recent work in literary studies has been given over to how—or how not—to read. While this has always been a central concern of the field, it has recently attained both a new dimension and a new urgency. Literary scholars are re-considering not just how we teach students to read, but how we, as scholars, read: our motivations and our goals in approaching a work of literature, an historical text, or even a work of scholarship. So-called “suspicious,” or skeptical, reading practices, those aimed at uncovering or revealing the hidden machinations of power at work in a given cultural artifact, have come to be seen, somewhat ironically, with

skepticism.¹³ I have long been sensitive to this line of thinking, either due to my particular field of study (Early American literature, a field long resistant to theory), my institutional home (an urban, community college, where I teach composition and general education courses), or, perhaps, a romantic affinity for getting lost in a good book. Encountering the field of literature and medicine, as I did just as I was completing my doctoral work, has corresponded well to an interest in understanding not only how works of literature have worked to facilitate and re-inscribe the uneven distribution of power, but also how works of literature perform a more pragmatic function, a kind of everyday repair for readers and writers.

In her description of reparative reading, Sedgwick begins by identifying the limited utility of what she calls “paranoid reading,” a derivation of Ricoeur’s “suspicious reading.” For Sedgwick, paranoia, while useful as a scholarly position, carries with it key limitations. Primary among these is that paranoia is inherently anticipatory: “The first imperative of paranoia is *There must be no bad surprises*, and indeed, the aversion to surprise seems to be what cements the intimacy between paranoia and knowledge.”¹⁴ Paranoia attempts to de-fang surprise by anticipating the worst, to eliminate interruption by presuming it will come and that it will be bad. However, the omnipresence of precarity in end-of-life care lays bare the attempt to control surprises, to prevent the interruption from interrupting. If, as Sedgwick writes, “paranoia requires that bad news be always already known,” then as a stance it necessarily fails in the face of end-of-life care: we always already know the bad news of death.¹⁵ The problem becomes the next step—how do we live with death?

While working on this essay I found a small reporter’s notebook that I did not know I had taken from my parents’ home last summer. In it there are lists of things to do written by various members of my family. Each of us spent significant time at my parents’ house in the final year of Mom’s life, helping them with the logistics of senescence: trips to chemo and the neurologist, re-fitting showers and hanging a safety railing, meeting live-in caregivers and filling pill-boxes, cleaning the gutters. The notebook contains representative to-do lists from each of us, documenting the tasks we aimed to accomplish in the 48, 72, or 96 hours we were home. To-do lists imply a hierarchy and a temporality: first to last, easiest to hardest, most to least pressing, each crossed out as accomplished, one after the other. The following list appears in one brother’s handwriting:

1. Pills
2. Haircuts
3. AT&T
4. Freezer
5. Bills/Expenses
6. HELOC Application

Other lists in other peoples' handwriting similarly blend the activities of daily living with the bureaucracy of dying: "call hospice," "print pill instructions," "run to Staples," "arrange shopping—Peapod?" These lists, like my carefully crafted emails, represent another paranoid genre of end-of-life care. They are an attempt to act: to order, arrange, and complete, and thereby control the chaos, the interruptions. Mom always made lists, even before she got sick. The oldest pages in the notebook are in her handwriting: haphazard recordings of doctors' phone numbers, a reminder to call her sister, appointment dates, who to call about a hearing aid, the location of her grandson's volleyball game.

In defining reparative reading over and against paranoid practices, Sedgwick turns to a set of spatial metaphors. Paranoid reading, she points out, relies on a, "topos of depth or hiddenness, typically followed by a drama of exposure."¹⁶ The critic "uncovers," "reveals," or "makes visible" what is hidden in a text, thereby precluding the interruption and deflating the surprise.¹⁷ In identifying a reparative position, however, Sedgwick forgoes the urge to uncover, with its implicit assumption of perfection coming from exposure, in favor of what she terms a beside: a spatial topos that avoids both temporality and a dualism. To uncover requires a position from which one can do the uncovering, a position dictated by temporal and spatial distance. Reparative reading sees things beside one another, not as prioritized lists to accomplish. A to-do list is paranoid. It seeks to identify and forestall interruption and surprise through its temporal ordering and hierarchy.

My parents' deaths were interruptions, but they weren't exactly surprises. Not only were they both relatively advanced in age (Mom was 76, Dad 79), but they also had both been ill for some time. While Mom's initial diagnosis had come as a surprise, there was a fated-ness to it: her mother had also died of this rare form of cancer originating in the bile duct. While Mom received quality care and did enjoy a brief period of improved health following two rounds of chemotherapy and radiation treatment, her prognosis was never good. She died almost exactly a year after her diagnosis. Despite periods of respite in that year, times when she returned to her normal self, when the ravages of chemo seemed lighter, when she could muster outrage at the 2016 presidential campaign or coo at our baby daughter, the impending reality was always there, just beside, waiting to move into the foreground.

Dad's illness had been with us longer, and had, in a sense, been less surprising. Alzheimer's runs in his family—both his mother and his brother died of complications related to Alzheimer's, or Alzheimer's-related dementia. Dad's official diagnosis (via exclusion) had come five years earlier. The signs of his illness had been present for a few years before that: a misplaced object, a confusion about the day of the week, asking for someone who hadn't been there in the first place. Five years after his diagnosis, when Mom got sick, although he required 24-hour observation and re-direction, he was still able to independently complete his activities of daily

living. Following her death, Dad's cognitive and physical health declined rapidly, almost breathtakingly so. Receiving the call about hospice, and his death a little more than two weeks later, felt inevitable—surprises at which one had no right to experience surprise.

The death of a parent both should and shouldn't come as a surprise, whether they have been ill or not. Part of the nature of having a parent is the unavoidable fact of their death. Nevertheless, the experience presents a significant interruption in an individual's life. As Debra Umberson points out, it's a grief we all share: "The death of a parent is the most common cause of bereavement faced by adults in Western society."¹⁸ However, as Umberson's research further demonstrates, the loss of a parent marks a relatively new, demographically speaking, interruption. "Over the last hundred years, the timing and occurrence of these major events of adulthood [e.g., marriage, birth of a child, widowhood] have become much less predictable," Umberson writes.¹⁹ "During the same period, however, the death of a parent has become much more predictable an event of middle adulthood. In fact, today the death of a parent is the most predictable major life event of people aged thirty-five to sixty."²⁰ As generational milestones and family dynamics and structures change, parent death emerges as a paradoxical constant: a predictable interruption.

Umberson's research highlights a few salient aspects of the interruption that is the loss of a parent. Coming, as it often does, when the adult child has entered middle age, a parent's death marks a significant psychological transition. At a time when many adults have arrived at a settled career and family arc, the death of a parent presents, in one stress researcher's terms, a "disruption in that trajectory, a deflection in the path."²¹ That deflection, first and foremost, comes in the form of, for many adults, a first intimate engagement with illness and caregiving. "Prior to a parent's death, most adults have had little contact with illness and loss," Umberson writes.²² Engaging with a parent's illness and death compels many people to recognize "a different dimension of everyday life—and the difficulties associated with it."²³ Trips to the hospital and the doctor, navigation of financial or legal issues, and the intimacy of assisting with activities of daily living: all of these press on the children of dying parents, quite literally interrupting their careers and family lives. However, the decline and death of a parent presses emotionally in a manner unique among experiences of loss. As Umberson points out, the death of a parent makes us confront our own death, both physically and psychologically. Knowledge of our genetic connection to our parents presents a preview of our own decline. The abstraction of death gains concrete form in the cancerous cells dividing deep within our organs or the plaque building up on our nerve endings. Perhaps then it is not the fact of a parent's illness and death that comes as the surprise, but the proximity of it. The death of a parent registers emotionally or psychologically, yes, but also viscerally, biologically.

After Mom passed away, and in what turned out to be the final months of Dad's illness, I read and re-read works about death and dying. I sought, as I had been

trained to do, to understand what had happened to Mom, what was happening to Dad, and what had happened to my siblings and I, through those who had experienced it and thought about it and written about it before me. I read *The Odyssey*. I read Montaigne. I read C.S. Lewis's *A Grief Observed*. I read *How We Die*, Sherwin Nuland's touchstone analysis of the physical processes of the end of life.²⁴ I generally avoided illness memoirs, either about cancer or about Alzheimer's. They pressed too closely, offered meaning too easily. I wanted to read critically, to think from a position of distance and study, from a paranoid position, about death and grief.

I was avoiding, perhaps unconsciously, the kind of illness stories described by Arthur Frank as "Quest" or "Restitution" narratives. In *The Wounded Storyteller*, Frank divides the different forms of illness narratives into a variety of categories, including Chaos, Restitution, and Quest.²⁵ The latter two, as suggested by their names, posit an uplifting outcome, some form of positive experience emerging from the disruption of illness. In a recent review essay about disability, caregiving, and grief narratives, however, Frank recognizes the failure of such restorative arcs to capture the experience of disability or of terminal illness. In reference to terminal and caregiving narratives in particular, Frank points out that to integrate illness and death into daily life will always be, if accurately or truly told, off-putting.²⁶

Another work I read last fall was Meghan O'Rourke's *The Long Goodbye*, a memoir of her mother's illness and death, as well as of O'Rourke's own grief. In discussing her mother's cancer—specifically her vomiting through chemo—O'Rourke describes the sounds as harsh and other: "They rasped in her throat like little aliens trying to claw up and out. Of course, the disease is always seen as alien, never native."²⁷ It strikes me that what O'Rourke describes here, the alien clawing its way out, is not actually the cancer. It is the result of the treatment. But cancer, of course, is never native—it cannot be. But when it becomes terminal, I wonder if it at least is granted some kind of permanent resident status. In this way, the disease is not a mistake in cellular reproduction, but instead the inevitable outcome of living. O'Rourke writes of the anxiety which surrounds her mother's cancer and its treatment. "We would never 'know' exactly what was going to happen," she says about waiting for results from her mother's latest scan. "This was part of the terror of the disease: the way it turned life into a daily foreboding."²⁸ O'Rourke describes Sedgwick's paranoid position: an attempt to eliminate bad surprises, to uncover and to know. But when it is terminal, what does that knowledge do, I wonder, beyond induce more foreboding and more paranoia? To see it as native is to see it as part of the ending of life, not the end of life. I think there is something meaningful in that gerund—ending. It hovers between the noun and the verb. It is not simply a state of suspended action, but one of provisionality.

Interruption is temporal: we thought this was going to come after **that**, but suddenly *this* comes after **that**. Interruption demands a hierarchy and insists we prioritize: *this* interrupts **that** and we get frustrated because *this* is more important than **that**, or *this* interrupts **that** and our attention shifts because **that** is more important than *this*. Interruptions re-order time and demand our accommodation to a new order, a new narrative. Such a framing, however, views interruptions from a paranoid position. It views them as something to be anticipated, to be counteracted, to be prepared for: “no bad surprises.” What happens when we consider them from a reparative position – from a position that, in Sedgwick’s terms, seeks to avoid the hierarchy assumed in the temporal framing of paranoia, of the always anticipating? Sedgwick shifts our frame of reference from the temporal to the spatial, from *this then that* to *this beside that*. To place things beside one another is to accord them equal amounts of attention, to not distinguish between the interruption and the interrupted. But it is not a position of stasis, of inaction. It is, as Sedgwick’s term implies, a position from which to seek repair.

However, there was no repair for Mom or Dad. There was always going to be a bad scan, a more profound forgetting, a text message about hospice: inevitable senescence. Therefore, navigating the perpetual interruptions of end-of-life care requires occupying the provisional. What I think of as a provisional position is distinct from Sedgwick and Jurecic’s reparative in two key ways. First, there is less permanence in the provisional. It acknowledges its own temporal limit—things are safe, for now. The provisional also forgoes the ethos of repair implicit in the reparative, not because repair is not ethical, but because repair is not possible. In these two ways—impermanence and inutility—the provisional is uniquely attuned to confronting end-of-life care. I think we can see the provisional as a key, if often unacknowledged, feature of medical knowledge, medical narrative, and, by consequence, of narrative medicine.

Provisionality seems to characterize narrative medicine. In the summer of 2016, just before Mom’s illness was revealed, and just as Dad’s was becoming unmanageable, I attended a lecture given by Rita Charon at Ohio State University. Charon spoke about what she termed “narrative humility,” a concept she returned to in response to a question about the kind of reading required by those of us interested in narrative medicine. With reference to Sedgwick’s reparative reading Charon described her approach as a “tentative” form of reading.²⁹ Elsewhere, Jurecic describes reparative projects as those that “attend to the significance of the local and contingent” with the limited goal to “perform repair in the moment for the moment.”³⁰ And the provisional returns more fully in her analysis of *The Diving Bell and the Butterfly*, an application of Sedgwick’s reparative reading:

Writers are pressed by circumstances to address how the experience of illness causes fixed ideas and narratives to fall away. Through the act of writing, these writers recreate, *at least temporarily*, a more coherent sense of themselves

and their lives. When writers or readers hold both rupture and beauty in view at the same time, understanding them to exist in relationship, then they see from a reparative position.³¹

I did not know it then, but that text message notification on my laptop, the one informing me that we had to decide for Dad—hospice or feeding tube—compelled me to occupy a provisional position. There was rupture: news of Dad’s imminent death, no matter how unsurprising, was an interruption. But there was also beauty in that moment: that I was to spend that evening teaching.

Those two things, that rupture and that beauty, existed in relationship for that moment not merely by their coincidence in time, but also because of the fact that I was teaching that night. Teaching is the place in which I most often find myself occupying a provisional position. Teaching, according to education researcher Gary Thomas, necessarily draws on a form of knowledge defined by Aristotle as *phronesis*: “or, in today’s terms, practical reasoning, craft knowledge, or tacit knowing: the ability to see the right thing to do in the right circumstances.”³² When we look up from the podium, enter a seminar discussion, or answer a student query, we are occupying a provisional position from which, “we see links, discover patterns, make generalizations, create explanatory propositions—weak, vernacular or protoscientific theory...emerging out of experience.”³³ And teaching is the place where I, especially now, feel myself standing beside my parents. Both Mom and Dad dedicated their lives to education, teaching high school religion, geography, history, and politics for decades. They met teaching in a school, surrounded themselves with friends dedicated to the pursuit of justice through education, and their former students filled the funeral home at their respective wakes. They both still emerge beside me now, in the “tacit knowing” that characterizes the art of the classroom.

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If the beginning is an interruption, then endings presume knowledge.

The day after Mom’s funeral my wife and I, our six-month old daughter in-tow, packed our car and drove south-east from suburban Chicago to Knoxville, Tennessee. Our adopted home is Queens, but we were moving to Knoxville for that fall semester. My wife was an artist-in residence at the University of Tennessee and I was on parental leave from my regular academic appointment at Queensborough Community College. So, instead of tracing the familiar straight line of Interstate 80 back east, a drive we have made countless times in the last decade, we angled through Indiana and Kentucky, arriving at an unfamiliar apartment in an unfamiliar town in the middle of a humid, unfamiliar night. Two days later we drove again, south across the Tennessee River and a few miles into the foothills of the Smoky Mountains, to watch the complete solar eclipse, the shadow of which angled across the southeastern US in August of 2017. It was a last-minute decision: we still had not

completely unpacked the car and my wife would start teaching at a new institution a few days later, but the chance to see the eclipse from within the so-called “Path of Totality” felt like something we should not pass up. We were unprepared: we overpaid for knock-off eclipse glasses in a gas station parking lot, googled how to keep an infant from looking directly at the sun, and wandered until we found people gathered in a small municipal park in the town of Alcoa, Tennessee.

We carried a blanket to protect our daughter’s eyes and walked a short way into the grass just as a sliver of dark began to creep across the sun. A few other people sat, scattered in lawn chairs around the park, heads craned backwards. My wife and I both took brief glances through our paper eclipse glasses as the darkness grew on the face of the sun. Anxiety about damaged retinas made us hesitant to look steadily, so I fashioned a makeshift camera obscura. Locating the proper orientation took a moment, but I turned my back to the sun and there it was: a pinhole-sized circle of light, partially obscured and bouncing erratically on a sheet of drawing paper. We snapped pictures with our phones, not of the sun, but of that oddly shaped dot of light on the paper. As the shadow of the moon crested the pinhole of light the world beyond the edges of the paper changed. The thick air around us chilled perceptibly. The wind blew. A street light above our car switched on with a buzz. I heard birds and bugs, and, almost without noticing it, the light changed – it grew dark, but not like dawn or dusk. In my memory it looks green, not right. It was the world, our world, my world, but something was off. Then it ended. We drove back to Knoxville. Mom was still dead. Dad was still alone, lost in their house and in his own mind. A few weeks later I would read Meghan O’Rourke quoting La Rochefoucauld: “Death and the sun are not to be looked at steadily.”³⁴ Uncovering would not produce knowledge, not useful knowledge anyway. But, just as I stood within that changed light, felt more than really saw the eclipse, so I felt Mom’s death, just as I would Dad’s eight months later, by viewing it somewhat askance.

Studying and teaching the health humanities has offered me a way to look at my parents’ end-of- life care and deaths, if not steadily, then provisionally. I find them in my readings and in my classrooms—like the one I will enter again tomorrow, to begin another semester, as I write this. In the afterword to a posthumously published collection of his lectures, Mary Rorty describes her husband, the late pragmatist philosopher Richard Rorty, as thinking in genres. He considered “Physics, or mathematics, or medicine,” she writes, “[as] all representing ways of finding (or imposing) order on the chaos of the world around us so we could talk about it to each other.”³⁵ So that we could talk to each other—across the divides, through the interruptions, placing our genres beside one another, so that we can be safe, for a moment.

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- ¹ Arthur Frank, *The Wounded Storyteller* (2nd Ed.), University of Chicago Press, 2013, 65. Print.
- ² Throughout this essay I employ the term health humanities, rather than the more widely-used medical humanities, to describe my field of inquiry. My thinking on this follows Sari Altschuler, who identifies the disciplinary limitation (and authority) implied by the modifier “medical.” The more capacious “health” better reflects the complex and inter-connected ways that human beings encounter and understand, both within and beyond “medical” contexts. See Altschuler, “Health (and the) Humanities in Early America,” *Early American Literature* 53.1 (2018): 169-84. Web. 10 January 2019.
- ³ Ann Jurecic, *Illness as Narrative*, University of Pittsburgh Press, 2012, 14. Print.
- ⁴ *Ibid.*
- ⁵ *Ibid.*
- ⁶ Eve Kosofsky Sedgwick, *Touching Feeling: Affect, Pedagogy, Performativity*, Duke University Press, 2003, 146 (emphasis original). Print.
- ⁷ *Ibid.*
- ⁸ Jurecic, *Illness as Narrative*, 115.
- ⁹ Rita Charon, *Narrative Medicine: Honoring the Stories of Illness*, Oxford University Press., 2006, 5. Print.
- ¹⁰ *Ibid.*, 6.
- ¹¹ Margaret Edson, *W;t*, Farrar, Strauss and Giroux, 1999. Print.
- ¹² “Cheating Death; Ageing” *The Economist* 420.9002 (2016): 7. The theory of the “disposable soma,” or the idea that the body’s primary function is to pass on genetic material through reproduction, thereby leading to its planned obsolescence once the age of fertility has been passed, derives from the work of biologist Thomas Kirkwood. The specifics of Kirkwood’s theories are first elaborated in “Evolution of Ageing,” *Nature* 270 (1977): 301-4. Web. 10 January 2019.
- ¹³ The term “suspicious reading” was first identified by Paul Ricoeur in *Freud and Philosophy: An Essay on Interpretation* (Yale UP), 1977, 32-6. Print. In addition to Jurecic and Sedgwick, the position has been elaborated most forcefully by Bruno Latour, “Why Has Critique Run Out of Steam?: From Matters of Fact to Matters of Concern,” *Critical Inquiry* 30.2 (2004): 225-48, Web 10 January 2019; and Rita Felski, *The Limits of Critique*, University of Chicago Press, 2015. Print.
- ¹⁴ Sedgwick, *Touching Feeling*, 130.
- ¹⁵ *Ibid.*
- ¹⁶ *Ibid.*, 8.
- ¹⁷ *Ibid.*
- ¹⁸ Debra Umberson, *Death of a Parent*, Cambridge University Press, 2003, 19. Print.
- ¹⁹ *Ibid.*, 79.
- ²⁰ *Ibid.*
- ²¹ *Ibid.*, 17.
- ²² *Ibid.*, 96.
- ²³ *Ibid.*
- ²⁴ Homer, *The Odyssey*, trans. Emily Wilson, W. W. Norton, 2017. Print; Michel de Montaigne, *The Complete Essays*, trans. M.A. Screech, Penguin, 1993. Print; C.S. Lewis, *A Grief Observed*, Harper Collins, 2001. Print; Sherwin B. Nuland, *How We Die: Reflections on Life’s Final Chapter*, Vintage, 1995. Print.
- ²⁵ Frank, *The Wounded Storyteller*, 75-7 and *passim*.
- ²⁶ *Ibid.*, “Writing Oneself Back In: Narratives of Care, Grief, and Loss.” *Literature and Medicine*. 35.1: 2017 (229-235). Web. 10 January 2019.
- ²⁷ Meghan O’Rourke, *The Long Goodbye: A Memoir*, Riverhead Books, 2011, 33. Print.
- ²⁸ *Ibid.*, 36.
- ²⁹ Rita Charon, “The Shock of Attention: Discoveries of Narrative Medicine,” Project Narrative Summer Institute, Ohio State University, 13 July 2016.
- ³⁰ Jurecic, *Illness as Narrative*, 106.

³¹ *Ibid.*, 109 (emphasis mine).

³² Gary Thomas, “The case: generalisation, theory and phronesis in case study,” *Oxford Review of Education*, 37.1 (2011), 23. Thomas elaborates on these ideas in a more recent book, Thomas & Kevin Meyers, *The Anatomy of the Case Study*, Sage Publications, 2015.

³³ *Ibid.*, 27.

³⁴ O’Rourke, *The Long Goodbye*, 182.

³⁵ Mary Rorty, “Afterword,” *Philosophy as Poetry*, University of Virginia Press, 2016, 65.