

2019

Embracing the Negative Capability of Dementia

Amanda M. Caleb

Misericordia University, acaleb@misericordia.edu

Follow this and additional works at: https://repository.stcloudstate.edu/survive_thrive

Recommended Citation

Caleb, Amanda M. (2019) "Embracing the Negative Capability of Dementia," *Survive & Thrive: A Journal for Medical Humanities and Narrative as Medicine*: Vol. 4 : Iss. 1 , Article 12.

Available at: https://repository.stcloudstate.edu/survive_thrive/vol4/iss1/12

This Article is brought to you for free and open access by theRepository at St. Cloud State. It has been accepted for inclusion in *Survive & Thrive: A Journal for Medical Humanities and Narrative as Medicine* by an authorized editor of theRepository at St. Cloud State. For more information, please contact rswexelbaum@stcloudstate.edu.

Embracing the Negative Capability of Dementia

Cover Page Footnote

I am grateful to my father's willingness to publish portions of our conversation in this article. Writing and revising this article was supported by Misericordia University's Faculty Research Grants.

Embracing the Negative Capability of Dementia

Understanding how Alzheimer's is perceived and represented can help interrupt and change the experience of the disease for those who suffer, those who anticipate suffering, and those who care for its victims.¹

[...] then on the shore
Of the wide world I stand alone, and think
Till love and fame to nothingness do sink.

John Keats, 1818²

For nearly two years now, my family has been grappling with the unknown, but suspected: my father's dementia—undiagnosed to date, because he refuses to see a doctor and seek a diagnosis. All the signs are there: memory loss, loss of words, confusion, disorientation, depression, personality changes, and a family history that includes his father, his uncle, and most likely their father. But my father is a recently and reluctantly retired pediatrician, and he refuses to even talk about dementia, let alone consult a physician. My family has, at one time or another, thought that it could be anosognosia, which frequently occurs with dementia. For a long time, my understanding of such reluctance came from Robert Klitzman's reflection on his interviews of doctors who had become patients: "I was struck by the levels of denial these doctors evidenced when they were facing the horrors of illness—how their fears as patients overcame their objective knowledge as physicians."³ Surely fear was the reason, I thought: he does not want confirmation of what he knows is true because of what the prognosis will be.

*

Fear, or rather uncertainty, is at the heart of John Keats's poem "When I Have Fears That I May Cease To Be," which I have taught to students for well over a decade, and which I use on the first day of my Medical/Health Humanities classes to expose students to course themes and techniques, such as the role of uncertainty in medicine, individual views of disease and death, and applications of narrative medicine. The poem is often read as autobiographical: Keats, a doctor-poet who was diagnosed with tuberculosis in the early nineteenth century, laments that he will not achieve fame and love before his inevitable early death, yet also recognizes his insignificance in the world, both spatially and historically. Here Keats evokes his concept of negative capability, the idea that "man is capable of being in uncertainties.

¹ Anne Davis Basting, "Looking Back from Loss: Views of the Self in Alzheimer's Disease," *Journal of Aging Studies* 17 (2003): 88

² John Keats, "When I Have Fears That I May Cease to Be," in *Keats's Poetry and Prose*, ed. Jeffrey N. Cox (New York: Norton, 2008), 118, lines 12-14.

³ Robert Klitzman, *When Doctors Become Patients* (Oxford: Oxford University Press, 2008), 25.

Mysteries, doubts, without any irritable reaching after fact and reason.”⁴ To dwell in these uncertainties is not the rejection of facts, but rather the acceptance that some things cannot be explained and the mind can accept conflicting concepts without the need for rationalizing such differences.

In the poem’s moment of negative capability, Keats does not seek or need a clear answer or framework on how to reconcile ambition with insignificance; rather, he reflects emotively on this uncertainty and asks us to do the same. The final lines of the poem imply a resolution that the title ultimately denies: the speaker tells us: “I stand alone, and think / Till love and fame to nothingness do sink.”⁵ Critics have read these lines in many different ways: for instance, Jamey Hecht argues that by withdrawing to this isolated space, “where meaning is private or not at all—the speaker can hope to outlive meaning.”⁶ This reading offers more certitude and resolution than the title suggestions, which indicates the fears are reoccurring and not so easily unraveled: “*When* I have fears that I may cease to be” immediately notifies the reader that the poem will not provide a resolution to these fears (my emphasis).

The poem instead offers insight on the nature of thinking and of refusing single definitions of self. Steven Connor argues that “Keats has no intention of abandoning love and fame. Instead, he tells us, he just thinks, which is exactly what is needed to make his ambitions possible of realisation, precisely by making a space in which his thoughts can be thought [...] that allows the renegade thoughts to become the objects of that thinking.”⁷ To think, and for those thoughts to become the objects of the poem, allows the speaker to dwell in the possibility of success and fame, but never in the full realization of either. Here is the moment of negative capability that defines the poem: the speaker desires fame and love, yet also realizes the insignificance of such desires in light of the expansive world. He does not abandon such desires, nor does he actualize them in the narrative of the poem: he thinks, returns to his fears, and refuses to accept either viewpoint as definitive, but rather embodies both simultaneously.

*

Despite my years of teaching Keats’s poem, only in the last year did I start to recognize the connections between the poem and my father’s experience of health and illness, thanks to one student’s anonymous response to the poem. I asked the students to respond to the prompt, “When I Have Fears....,” filling in the blank in

⁴ John Keats, Letter to George and Thomas Keats, 21 December 1817. In *The Letters of John Keats*, ed. H E Rollins (Cambridge: Cambridge University Press, 1958), 1:193-4.

⁵ Keats, “When I Have Fears,” lines 13-14.

⁶ Jamey Hecht. “Scarcity and Poetic Election in Two Sonnets of John Keats.” *ELH* 61.1 (1994): 116.

⁷ Steven Connor, “Thinking Things.” An extended version of a plenary lecture given at the 9th annual conference of the European Society for the Study of English (ESSE), Aarhus, Denmark, 25 August 2008 and as the *Textual Practice* lecture, University of Sussex, 14 October 2009.

<http://www.stevenconnor.com/thinkingthings/>

any way they saw fit. As this was a first-day activity, I offered anonymity so they would feel comfortable—very soon, they did not need this extra security. One student submitted the following, which resonated immediately: “When I Have Fears that I might not be remembered or remember others, I am sad. I don’t want to forget, and I don’t want people to forget me!” Half of this response was unsurprising: as the poem is about the impact one has on others and the world, it is common that students fear that what they have done with their lives may be forgotten—indeed, several students responded in a similar manner. However, the notion that one might forget, rather than be forgotten, was not something I had encountered before. I began to imagine how the student was responding to the poem: perhaps those final lines suggested the speaker forgetting, or trying to forget? What if the return to fears was about an inability to remember how the speaker had responded previously? What if the poem was as much about not knowing as it is about knowing? While such readings seem counter to what we know of Keats’s life, that did not matter: the poem may have revealed to this student, and did reveal to me, a new way of responding to it that embodied negative capability as a cognitive health concern.

Immediately I thought of my father: would he read the poem in a similar manner? There are several studies about the value of using poetry to enhance empathy in medical students, to improve doctor-patient relationships, and to offer a therapeutic outlet for doctors and patients alike.⁸ Equally, there is compelling research on the value of reading poetry to patients—but virtually nothing on doctors as patients reading poetry.⁹ My own preoccupation with my father’s health, coupled with how I imagined this student responded to the poem, inspired me to try this different approach to discussing dementia with my father.

*

“I want to talk to you about a poem I teach in class and see what you think of it.” I began with a very broad description of what our conversation would entail: my intention was to be a listener, not an instructor. Although he struggled reading the poem aloud—a reminder of some of his cognitive challenges—my father responded thoughtfully to it, and while his responses may have drifted from the

⁸ Frank J. Wolters and Marjo Wijnen-Meijer, “The Role of Poetry and Prose in Medical Education: The Pen as Mighty as the Scalpel?,” *Perspectives on Medical Education* 1.1 (2012): 43-50; William Foster and Elaine Freeman, “Poetry in General Practice Education: Perceptions of Learners,” *Family Practice* 25.4 (2008): 294-303; Elizabeth A. Davies, “Why We Need More Poetry in Palliative Care,” *BMJ Supportive & Palliative Care*, 23 March 2018. doi: 10.1136/bmjspcare-2017-001477. There are also a number of facilities that have developed poetry workshops for patients, including for those with dementia and Alzheimer’s Disease, such as the Alzheimer’s Poetry Project (www.altzpoetry.com).

⁹ Sherry Reiter, “Enhancing the Quality of Life for the Frail Elderly: Rx, the Poetic Prescription,” *Journal of Long Term Home Health Care* 13.2 (1994): 12-19; Marvin Wexler, “A Poetry Program for the Very Elderly—Narrative Perspectives on One Therapeutic Model,” *Journal of Poetry Therapy* 27.1 (2014): 35-46; Joan Healey et. al., “The Potential Therapeutic Benefits of Reading Poetry to Nursing Home Residents: The Road Less Travelled?,” *Journal of Poetry Therapy* 30.3 (2017): 153-65.

poem, he came back to the text in the end. While such an approach might have risked missing his story entirely by encouraging analysis over storytelling, the poem allowed for triangulation: when he addressed topics that were less comfortable—such as memory loss—he transposed his own experience onto the poem. Given that we have never had a relationship built on sharing feelings, this approach seemed the most valuable in encouraging such conversations. Indeed, my father appeared more comfortable disclosing information under the guise of interpreting the poem.¹⁰

The conversation was not linear: we moved from the present to the past, from the near past to the recent past, and a return to certain stories several times. At first glance, the conversation might have seemed disorganized, or at the very least repetitive, but I would argue that such a description would be misleading; the narrative was very structured, but it was my father's structure and not mine. In other words, the conversation required me to move away from a linear, a cause-and-effect, or any other traditional narrative to see his logic, which was just as valid as mine—really, more so because it was how he made sense of his past and present. While resembling the chaos narrative Arthur Frank describes, the story my father told did not quite fit the mold: he was capable of reflection, but only as embodied through the poem itself and reconstructed through the poem.¹¹ Although not directly a story of illness, the act of storytelling was an embodiment of the experience of illness; as such, his narrative offered the possibility of “*repair*[ing] the damage that illness has done to the ill person's sense of where she is in life, and where she may be going.”¹² Certainly I hoped to achieve this repair, not only for my father's sense of self but also as an act of strengthening our relationship.

Recent scholarship on dementia narratives have focused more on how identity is created through narrative, largely through positioning analysis, which looks at how one sees oneself and others in the world.¹³ Expanding on this theory with relation to narrative, Michael Bamberg suggests positioning takes place at three levels: within the story world (“How are the characters positioned in relation to one another within the reported events?”), as part of the storytelling (“How does the speaker position him- or herself to the audience?”), and as part of identity formation

¹⁰ This approach is derived from TimeSlips, a non-profit group that reimagines care for the elderly and those with memory loss by encouraging them to tell stories rather than recall memories. Preliminary research on TimeSlips has yielded positive results, including better patient-caregiver relationships. See: Thomas Fritsch, et. al., “Impact of TimeSlips, a Creative Expression Intervention Program, on Nursing Home Residents with Dementia and Their Caregivers,” *The Gerontologist* 49.1 (2009): 117-27.

¹¹ Arthur W. Frank, *The Wounded Storyteller: Body, Illness, and Ethics* 2nd ed. (Chicago: University of Chicago Press, 2013), 98-99.

¹² *Ibid.*, 53.

¹³ See, for instance: Maria Castro and Kitty Clark-McGhee, “A Narrative Analysis of Poetry Written from the Words of People Given a Diagnosis of Dementia,” in *Constructing Narratives of Continuity and Change*, eds. Hazel Reid and Linden West (New York: Routledge, 2015), 144-58; Matti Hyvärinen and Ryoko Watanabe, “Dementia, Positioning, and the Narrative Self,” *Style* 51.3 (2017): 337-56.

(“How do narrators position themselves to themselves”).¹⁴

My sense of our conversation was that it could be divided into these three levels as related to the types of narration that occurred chronologically during our conversation: explication of the poem, personal storytelling, and textual connections to self. My application of positioning analysis to this conversation is muddled to say the least: typically positioning analysis looks at the individual’s story and considers how one or more of these levels are represented by the storyteller in the act of storytelling. In the case of my father, there were three different stories being told: that of the poem, that of my father’s past, and that of my father’s relationship to the poem. However, these stories are related through his retelling and interpretation; in other words, he was always in the act of telling a story even as he was analyzing the poem.

In discussing the poem, my father could concentrate on the story world that he saw in the text, which was driven by how he understood the speaker’s motivations and fears. In his personal storytelling, the positioning shifted, whereby the focus was on the relationship between the two of us. Finally, his explicit connection of self to the poem—separate from his explication and exhibited after his storytelling—demonstrated a collapsing of narrative styles that offered possible insight into how my father understands himself in relation to both a fictional narrative and within his own stories. When viewed as a whole, the conversation as narrative demonstrates my father’s progressive understanding of his own identity as embodied in the Keats poem.

*

My father’s explication of the poem began with identifying what fears he saw in the poem, namely as those associated with being successful and being remembered. When explaining these fears, he embodied the first person: “Will people still remember me? I don’t want it to happen. If I can’t walk, or I can’t speak, or I can’t remember, then I’ll talk as long as I can talk, as long as I can write, or someone can write for me, but all of these things that I have can still be put down, are still important.” After remarking on these fears—some of which go beyond the typical reading of the poem—he quickly noted, “these are what’s in the poem, *his* fears” (his emphasis). The addendum to his explication indicated a separation of self from the poem: the use of guarding assured that I understood his explanation was not about his own fears, even as I made connections between the litany of fears and my father’s personal health experiences, including a hip replacement and his undiagnosed dementia. Notably, his response to fears of being less able (cognitively or physically) were to talk and to write—specifically to record what is important to the speaker. This metacommentary that reflected on my taking notes of our conversation struck me as a sense of awareness of narrative itself: while my father

¹⁴ Michael G.W. Bamberg, “Positioning Between Structure and Performance,” *Journal of Narrative and Life History* 7. 1-4 (1997): 337.

was not engaging in the act of telling a “bigger narrative” about himself, he was constantly sharing small stories, and these stories are equally valid in sharing and ultimately preserving his identity.¹⁵

When I asked him to explain where he saw memory loss as part of the poem, my father pointed to the last two lines: “Of the wide world I stand alone, and think / Till love and fame to nothingness do sink.”¹⁶ “He forgets,” my father explained, “that’s why he has to keep reciting the poem.” Such a reflection alluded to what we might imagine to be the dementia narrative, one that features repetition of stories, ideas, etc. However, my father’s insight was more profound than mere observation: to retell the poem was not forgetfulness, memory-loss, or anything like it: it was deliberate because the words matter, and the story needs to be told. Thus, the repetition of a story might well be because of its significance, that it needs to be told more than once; not simply because the individual forgot he had already told the story, but rather because the story resonates with the individual and how the individual sees himself in the world.

Framing repetition in this manner alters how I viewed a large portion of our conversation, particularly those associated with his personal stories. I asked my father if he had any fears, either professionally or personally, in an attempt to encourage my father to confront his memory loss directly; this approach was naïve at best, but did reveal more about how stories shape my father’s present and his sense of self. Although he initially denied having any fears, much of the interview focused on his individual fears. For instance, in discussing professional fears, he offered these two reflections:

1. I didn’t have any fears. And I’ll explain. [pause] But I know it was there. It was there because some people, some say psychologically a whole bunch of different things, and I see it. Initially when I saw it, I had been a couple of years, and I’m the one: I got through it and I know the newest things and everything else like that.
2. You’re going to go on and do the best you can, and you did it. And there are times you go, “I did it.” Well, what did I do? It was what I didn’t do. It was something way out there, and you might see it once in 60 or 70 years, and that I didn’t like. You’d say, “I think this,” but I have to go to the book. I didn’t like that.

What is very clear in these two responses is that, not surprisingly, he had professional fears, and these are tied to the expected knowledge of a physician. His initial distancing of himself from the fears expressed in the poem indicates a positioning

¹⁵ While there is a lot of research on bigger narratives—the more polished interviews or personal stories—scholars of positioning analysis have argued for the value of smaller stories—the everyday, often unplanned conversations—that suggest regular identity formation. See Cate Watson, “Small Stories, Positioning Analysis, and the Doing of Professional Identities in Learning to Teach,” *Narrative Inquiry* 17.2 (2007): 371-89.

¹⁶ Keats, “When I Have Fears,” lines 13-14.

that allows for the physician identity formation, one that projects authority and confidence. However, this identity collapsed in the act of storytelling: even with a lack of clear details, it is apparent that my father's fears of not knowing, or making the wrong decision, are parallel to Keats's fears of not gaining fame from his writing: both are possible results when time limitations are in place.

The same can be said of my father's personal fears, which were expressed as regrets in a number of anecdotes. He spent nearly half of our conversation recounting his time volunteering with the Boy Scouts, enumerating several programs he developed to help with life skills, to include girls in activities, and to help encourage parent participation. Yet, despite all these stories, he still concluded:

What bothered me is that at the end, Mom wanted to do stuff, and I don't blame Mom, and you guys too. And that's what I felt: if there was one thing once, that was it. That things that we didn't get to do, that I don't get to do with you. With your brother, sometimes with baseball, but if I was on call I couldn't do it. [long pause] That, that bothered me, and your mother did all of that, and I am not doing that.

The regret of time prioritization is clear; so, too, is the verb slippage that suggests both past and present. His regrets were both what he didn't do, and what he is not doing currently; in expressing both past and present—and in the content of his regret—he brought me, as listener, into the conversation. My father's personal regrets were related to his audience, and given that these regrets were tied to his professional dedication, these fears are more closely aligned than they may seem. In other words, to be a knowledgeable, successful, and compassionate doctor requires time, but that time, for him, came at the cost of spending time with his family. The implication here was the continued desire to spend time with his family: he expressed a keen awareness of what he had missed out on, and, implicitly, what he might miss now. Although this was not an acknowledgement of his dementia, it did reveal a loss that paralleled his interpretation of the poem and the speaker's fears.

After this reflection (about 45 minutes into our hour-long conversation), a discursive change occurred: my father began to continually reference the poem and pick it up with each reference. Up until this point, there was a notable separation of his explication of the poem (in the first five minutes of our conversation) and his personal reflections; the final minutes of our conversation was defined by how he related himself to the poem. The shift came from a reflection on loss, which brought him back to the poem itself.

In these later reflections on the poem, he focused on the relevance of the poem to life, particularly in relation to the word "cease" and the final lines of the poem. In discussing the word "cease," he explained how he would talk to kids (presumably patients) about the poem, asking "what these things mean." In imagining this conversation, he stated that kids would say, "Well, I don't want to die." For him, that was wrong: "Cease doesn't mean die. I can't get over the number of people who don't know what words mean. And cease: what do you think it

means? What happens when cease?” From there, he shared how he practiced medicine, combing stories of treating patients with conversations with parents: for him, they were all one event, but it was clear that there were multiple people and stories involved. The stories were about time: taking the time to have conversations with kids, to spend time with kids, which related back to his personal regrets and fears. His overt conversation about time and the time slips that happened as part of this conversation paralleled his earlier fear about not having enough time, both personally and professionally. The anecdotal stories, tied to the poem, were as much about his identity as they were about the individuals in the stories. In many ways, he reminded me of Keats: he was speaking a truth about others that was also a truth about himself.

In returning to the final lines of the poem at the end of our conversation, my father provided a reflection that collapsed the distanced explication of the poem and his intimate memories. He returned to the word “cease” at the end of our conversation, again echoing his statement that cease does not mean death; however, he did describe a metaphorical death related to both communication and identity: “I can still be alive, that we put these things and say that’s alive, but I can’t do things that I did before, I can’t do them as well, I can’t do them new. And so I’m alive here, I can hear and I can talk, and people talk to me, but is it me any longer? No. Do people look at me and other people are coming and this is death, and I don’t want that.” His reliance on the first person indicated an affiliation of self with the text: I found myself questioning if he was describing the motivations and viewpoints of the speaker or his own. The description also depicted a static identity, one that cannot create (or do) anything new, and one that is not his sense of self. In positioning the literary self with the physical self, he questioned who he was in relation to the loss of ability. While he never indicated dementia nor memory loss, the descriptions he provided—of feeling worthless and loss of identity and autonomy—mirrored feelings expressed by people with early dementia.¹⁷

In his final discussion of the poem’s last lines, he indicated his relationship to those lines:

“Of the wide world I stand alone, and think / Till love and fame to nothingness do sink.” And you take that, “stand alone.” How many people stand alone? And how many people realize that? And how many people know how to deal with that, etc. [...] I’m this, or I’m this. What do I want to do for my family? You don’t know what it is, and what it will be. I read it, and while we were talking, there are some very good things in there, and it’s something people are afraid of. [...] There it is right there. He died, he died. It’s there. What happens to it? It’s gone.

This comment has several pronoun shifts, from generic second person (how a

¹⁷ Els Steeman, Bernadette Dierckx De Casterlé, and Jan Godderis, “Living with Early-Stage Dementia: a Review of Qualitative Studies,” *Journal of Advanced Nursing* 54 (2006): 722-38.

person might feel) to first-person interpretation. Such shifts occurred several times in his discussion of the poem: what stands out more in this final reflection is the use of the word “it.” He never defined his usage of “it,” which is reflective of the word’s association with the unknown and with loss. One might read this use of a dummy subject as the embodiment of his inability to recall specific loss, i.e. memory loss. However, in light of his earlier claims about the poem, I would argue his use of “it” referred to a number of different things that the speaker had and then lost: fame, love, etc. were there, and then they are gone, taken away. I read this meaning in combination with his use of the first-person as an implied connection between what the speaker has lost and what he might lose given his health. If my father’s great regret is the lack of time he spent with his family, then the prospect of losing more of that time is as much what he is afraid of as what others are afraid of.

I took a risk at the end of our conversation: I asked him if he thought the poem had anything to do with memory loss and dementia and if he felt any connection to the poem because of his memory loss. Immediately he became angry with me: “why the hell does everything have to be about my memory? My memory is fine—people just don’t listen.” The final comment stung: I closed down the communication line, and he had openly accused me of something I secretly thought was true—we were not listening to him. Amy Robillard, in reflecting on her mother’s dementia, notes, “If we cannot hear, if we refuse to hear, what happens to the narrative?”¹⁸ I would go one step further: what happens to the self if the narrative is ignored? My father had revealed all he wanted to—about his fears, how he saw himself and his relationship to others—and I was demanding a label of self that did not feel like self to him because I refused to listen to his narrative as he wanted to tell it.

*

Listening to my father during our conversation—and reflecting upon it—changed how I understand him as a person and with regard to his health. The act of close listening and reflecting have led me to think differently about Keats’s poem and my father’s experience. I cannot read the poem now without thinking of loss, but loss that is not merely about the physical but rather also about self. In re-reading the poem, I see the speaker’s lament of not writing all his thoughts and poems as indicating a loss of identity as much as a loss of talent and potential. Who is the poet if the poetry does not exist? The isolation at the end of the poem is echoed in the claim of “unreflecting love”: in other words, before the speaker reflects upon his fears, he already feels alone. Finally, the use of the modal in the first line—“*may* cease to be”—suggests possibility, not certainty: does the speaker have to cease to be? What other possibilities are there?

I would like to imagine there are a number of possibilities, especially when

¹⁸ Amy E. Robillard, “On Narrative Collapse: Dementia, Depression, and the Significance of Narrative Resources,” *Survive & Thrive*: 1.1 (2014): Article 8.

thinking about my father and his undiagnosed dementia. One such possibility is to dwell in the negative capability of the poem, our conversation, and his health. Negative capability, as Linda von Pfahl notes, is not passive: “rather it is the ability to do something, i.e., to assume other characteristics as a chameleon does.”¹⁹ What would it mean to stop trying to ascertain a definitive diagnosis and forcing our expectations of linear storytelling and precise conversations on his narratives—and instead become chameleon-like in our understanding of dementia? If “man is capable of being in uncertainties,” why isn’t my father capable of being in those same uncertainties about his health—and why can’t we understand his reluctance in this light? I am not suggesting people should ignore symptoms, nor delay medical diagnosis; rather, I want to imagine a space where my father’s sense of identity can be kept intact, and that he can be given the autonomy that he clearly feels a diagnosis would deny. His ability to assume the feelings of the speaker in Keats’s poem—and to align those with his own—indicates a much more complex sense of self and of narrative than what any of my family had thought before. His reluctance to seek a diagnosis and treatment is not simple fear of prognosis, nor is it necessarily anosognosia; rather, it may be as much about confirming suspicions as well as weakening his sense of identity.

If negative capability allows us to dwell in uncertainty, to refuse to reconcile contradictory aspects—in this case, the physical symptoms and the narrative experience—then it also allows for something even more profound: the ability to empathize. My father explicated the poem the way he did because he felt empathy for the speaker: what seemed like projection was really his experience of another’s sense of loss—that then became tied to his own sense of loss. My role is now to do the same: in reflecting upon my father’s narrative, I, too, need to dwell in the negative capability, of participating in the experience of ceasing to be as he imagines it. Rachel Hammer and her fellow researchers argue that “adopting a perspective of negative capability as offered by the practice of narrative medicine” is useful to “those working directly with addiction patients in light of the mysterious and often predictable nature of nature.”²⁰ I believe the same is true for those with dementia, suspected dementia, and memory loss. The conversation is not predictable, nor is the narrative: but the opportunity to understand those individuals’ sense of identity as tied to their stories provides immense opportunities “to foster empathy as remedy for the counterproductive stigma” for both the individual and their family members by “acknowledging the universal aspects of experiences like shame, anger, and grief narrows the gaps between self and other [...] where both are able to empower one another in the process of recovery.”²¹ Sharing such experiences directly with my

¹⁹ Linda von Pfahl, “The Ethics of Negative Capability,” *Nineteenth-Century Contexts: An Interdisciplinary Journal* 33.5 (2011): 455.

²⁰ Rachel R. Hammer, et. al., “The Experience of Addiction as Told by the Addicted: Incorporating Biological Understandings into Self-Story,” *Culture, Medicine, and Psychiatry* 36.4 (2012): 727.

²¹ *Ibid.* 456.

father was not going to happen: that is not the relationship we have ever had. However, using Keats's poem as a vehicle to share his fears, regrets, and sense of self proved an effective and emotional way for me to see his reluctance to seek a diagnosis as not a fear of what is, but rather a fear of what is lost when such knowledge is gained.

*

Despite my misstep at the end of our conversation, my father asked me a follow-up question after he calmed down: "can we talk about this again? I like this poem." Indeed, we did—and although he still has not sought medical treatment to date, he has continued to speak about the poem in relation to stories that define who he is. Opening this communication channel is a beginning, one that holds the possibility of seeking care that is driven by him, with respect for his experiences and his identity.

Bibliography

- Bamberg, Michael G.W. "Positioning Between Structure and Performance." *Journal of Narrative and Life History* 7. 1-4 (1997): 335-42.
- Basting, Anne Davis. "Looking Back from Loss: Views of the Self in Alzheimer's Disease." *Journal of Aging Studies* 17 (2003): 87-99.
- Castro, Maria, and Kitty Clark-McGhee. "A Narrative Analysis of Poetry Written from the Words of People Given a Diagnosis of Dementia." In *Constructing Narratives of Continuity and Change*, eds. Hazel Reid and Linden West, 144-58. New York: Routledge, 2015.
- Connor, Steven. "Thinking Things." An extended version of a plenary lecture given at the 9th annual conference of the European Society for the Study of English (ESSE), Aarhus, Denmark, 25 August 2008 and as the *Textual Practice* lecture, University of Sussex. 14 October 2009.
<http://www.stevenconnor.com/thinkingthings/>
- Davies, Elizabeth A. "Why We Need More Poetry in Palliative Care." *BMJ Supportive & Palliative Care*. 23 March 2018. doi: 10.1136/bmjspcare-2017-001477.
- Foster, William, and Elaine Freeman. "Poetry in General Practice Education: Perceptions of Learners." *Family Practice* 25.4 (2008): 294-303.
- Frank, Arthur W. *The Wounded Storyteller: Body, Illness, and Ethics*. 2nd ed. Chicago: University of Chicago Press, 2013.
- Fritsch, Thomas, Jung Kwak, Stacey Grant, Josh Lang, Rhonda R. Montgoemery, and Anne D. Basting. "Impact of TimeSlips, a Creative Expression Intervention Program, on Nursing Home Residents with Dementia and Their Caregivers." *The Gerontologist* 49.1 (2009): 117-27.
- Hammer, Rachel R., Molly J. Dingel, Jenny E. Ostergren, Katherine E. Nowakowski, and Barbara A. Koenig. "The Experience of Addiction as Told by the Addicted: Incorporating Biological Understandings into Self-Story." *Culture, Medicine, and Psychiatry* 36.4 (2012): 712-34.

- Healey, Joan, Chris Hopkins, Alex McClimens, and David Peplow. "The Potential Therapeutic Benefits of Reading Poetry to Nursing Home Residents: The Road Less Travelled?" *Journal of Poetry Therapy* 30.3 (2017): 153-65.
- Hecht, Jamey. "Scarcity and Poetic Election in Two Sonnets of John Keats." *ELH* 61.1 (1994): 103-20.
- Hyvärinen, Matti, and Ryoko Watanabe. "Dementia, Positioning, and the Narrative Self." *Style* 51.3 (2017): 337-56.
- Keats, John. Letter to George and Thomas Keats, 21 December 1817. In Vol. 1 of *The Letters of John Keats*, ed. H E Rollins, 193-94. Cambridge: Cambridge University Press, 1958.
- . "When I Have Fears That I May Cease to Be." In *Keats's Poetry and Prose*, ed. Jeffrey N. Cox, 118. New York: Norton, 2008.
- Klitzman, Robert. *When Doctors Become Patients*. Oxford: Oxford University Press, 2008.
- Reiter, Sherry. "Enhancing the Quality of Life for the Frail Elderly: Rx, the Poetic Prescription." *Journal of Long Term Home Health Care* 13.2 (1994): 12-19.
- Robillard, Amy E. "On Narrative Collapse: Dementia, Depression, and the Significance of Narrative Resources." *Survive & Thrive*: 1.1 (2014): Article 8.
- Steeman, Els, Bernadette Dierckx De Casterlé, and Jan Godderis. "Living with Early-Stage Dementia: a Review of Qualitative Studies." *Journal of Advanced Nursing* 54 (2006): 722-38.
- von Pfahl, Linda. "The Ethics of Negative Capability." *Nineteenth-Century Contexts: An Interdisciplinary Journal* 33.5 (2011): 451-66.
- Watson, Cate. "Small Stories, Positioning Analysis, and the Doing of Professional Identities in Learning to Teach." *Narrative Inquiry* 17.2 (2007): 371-89.
- Wexler, Marvin. "A Poetry Program for the Very Elderly—Narrative Perspectives on One Therapeutic Model." *Journal of Poetry Therapy* 27.1 (2014): 35-46.
- Wolters, Frank J., and Marjo Wijnen-Meijer. "The Role of Poetry and Prose in Medical Education: The Pen as Mighty as the Scalpel?" *Perspectives on Medical Education* 1.1 (2012): 43-50.