“I wrote letters? To you?”: Letters as Memory Prompts in Dementia Care

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Abstract: This paper explores a collection of letters that brought my mother and me together when physical distance separated us and, twenty years later, brought us some measure of togetherness in the face of dementia’s erosions. I worked as a volunteer teacher in post-war Uganda from 1986 to 1989, communicating with family and friends almost exclusively by handwritten letters. My mother promised to be my most faithful correspondent and she was. When my mother was diagnosed with Alzheimer’s disease in 2005, I knew that the more than two hundred letters we had exchanged in the 1980s would offer a version of her life before dementia’s processes began. This paper examines how reciprocity, relationality, interrupted presence, space-time, identity, gift, and voice resonated throughout 2007–8, when I used the letters as memory prompts during my weekly visits with my mother. The memory project extended the letters’ already complex temporality by juxtaposing two worlds: the cross-cultural world my mother and I were navigating in the late 1980s, and the unpredictable world of dementia care, where the letters sometimes elicited profound engagement, and sometimes—by their very epistolary nature—failed to bridge the unfamiliar distances opening up between my mother and me.

On August 16, 1986, I am hunched uncomfortably over my meal tray on a nine-hour flight from Amsterdam to Nairobi, writing the first of more than one hundred letters that I will send to my parents over the next three years. I am twenty-five years old, and I will not read Janet Gurkin Altman’s analyses of epistolary form for another twenty years. Exactly like the letter writers that Altman examines, though, I locate myself in relation to my addressees by mapping my temporal, spatial, emotional, and intellectual coordinates.1 Under the letter’s date, I write, “4 pm (Holland); 10 am (Akron); 9 am (Winnipeg),” simultaneously aligning myself to the Netherlands, where the flight originated; to Akron, Pennsylvania, where I have been at orientation training for the past week; and to Winnipeg, Manitoba, where my parents live and where I grew up. “Dear Mum and Dad,”2 I write to begin the letter proper, “Here I am at well over 30,000 feet and somewhere south of Greece. … I’m stuck in the middle of a capacity-filled 747, three seats and an aisle away from a window and have lost my bearings quite completely. I do know that I’m farther from home than I’ve ever been before.” When I land in Nairobi, I travel on to Ndejje, Uganda, where I will live for the next three years, working at a teacher training college in the aftermath of a civil war.

In 1986, email is still science fiction. In 1986 in Uganda, telephones are difficult to access and well beyond the budget of a volunteer teacher, and so, for the next three years, I communicate with family and friends almost exclusively by handwritten letter. Especially at first, before I begin to integrate into the community that is rebuilding at Ndejje, I use almost every moment that I am not teaching to write. The ironies of the situation are not lost on me. I could not have averaged more than two handwritten, 3000-word letters every week if I had been occupied with the considerable work of teaching science and mathematics to several hundred young women in a four-year
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training program at a highly respected teachers’ college. But the war left the college a ransacked shell and rehabilitation work is slow. Our first term began on August 29, 1986, with just fifteen students. Ironically, the war that created the conditions to which I had responded in Canada also created conditions in which I could write more, and more constantly, than I had ever written before.

I wrote because I was lonely, and I wrote because almost everything around me was unfamiliar, and I wrote because I was afraid. Some aspects of post-war life were deeply unnerving, but what frightened me most was the possibility that—separated from family and friends by 13,000 kilometers and excruciating postal delays—I was not real. Culture shock, especially in the first year, was a distraction from the alarming prospect that without my people, I no longer existed. “Please write soon,” I wrote again and again to my family and my friends, “I miss you terribly.” “Please write,” I repeated, “It’s a good thing I didn’t know how much I’d miss you, or I never would have come.” My life at Ndejje improved immensely, of course, with time, but the correspondence was never not freighted with existential anxiety. Will my letters make it to Canada, I wondered, the moment I relinquished them to the post? Will the responses arrive in Ndejje and when? And how will I continue being myself in the meantime?

I kept careful notes of when I mailed letters and to whom and equally careful notes of the letters I received and when they had arrived. The precarious, unpredictable communication of those three years never managed to be anything like what Liz Stanley calls “ordinary letter-writing,” and I returned to Canada in 1989 carrying every scrap of every missive that reached me. Most of my friends and family members saved my letters, too, so that when I created an informal archive of my time in Uganda, it housed over 800 separate pieces of correspondence. I saved the letters because my friends told me I should write a book, but I got busy with life in Canada and my archive went untouched for fifteen years. And then, in 2005, we learned that Geeske Venema, my jauntily intellectual mother, had Alzheimer’s disease.

My mother and I had been exceptionally close all of my life, our relationship characterized by animated, informally philosophical conversations on almost every subject imaginable. In 1986, knowing that I would be lonely in Uganda, my mother promised to be my most faithful correspondent, and she was, despite how much she disliked the physical work of writing. My mother was born left-handed in 1936 in the Netherlands, and she was forced to write with her right hand at school throughout the 1940s. The long-term effects of that misguided policy were her terrible handwriting and the fact that she never afterward wrote with any kind of physical comfort or pleasure. But from 1986 to 1989, she wrote anyway, faithfully, often at length, on average once every ten days, sending more than one hundred letters to me in Uganda, more than twice as many as my next most-regular correspondent.

The Alzheimer’s diagnosis confirmed my family’s worst fears and underscored the fact that I no longer had unlimited time to enjoy the mother I had known all my life. I had been reading about dementia care for several years before we received the formal diagnosis, and I knew that social and mental activity are crucial to retaining cognitive and physical functioning for as long as possible. Over the next years, I learned more, too, about the profound benefits of being present with people, paying attention to them, validating their feelings and experiences, and engaging them in activities they enjoy. Quality dementia care, it turns out, is not unlike letter writing, with its basis in what Kylie Cardell and Jane Haggis call “dynamic relational connectedness,” and its eagerness to maintain connection in the face of separation. Two years after the diagnosis, I designed a creative / research project to learn as much as possible about my mother’s life before our capacity for intimate conversation disappeared. For the next five years, I spent Friday afternoons with my mother, taking long walks and recording what we said as we told and retold family stories,
discussed the news, sang old songs, played word games, completed crossword puzzles, and read aloud. Over the years of our project together, my mother and I read parts of many books, but we began by focusing on the letters we had written to one another in the late 1980s, when we were farther apart than we had ever been before.

Among its many other effects, the Alzheimer’s diagnosis shone an unexpected light on my letter archive. I knew that my mother had rarely kept records of her life. She was reticent in most of her relationships, she was averse to the physical work of writing, and she understood herself to have few reasons to write. She carefully documented our family road trips, but those notebooks revealed little beyond mileage, gas costs, overnight destinations, and motel prices. By contrast—and almost miraculously—the 200+ letters my mother and I exchanged in the 1980s recorded a version of my mother’s life at least a decade before dementia’s processes began. By a lucky fluke, these were also the years during which my mother completed her undergraduate university degree, likely the most intellectually stimulating period of her adult life. In the months that followed the Alzheimer’s diagnosis, I began to imagine that our decades-old letters might be an entry back into the world my mother and I had shared during a vital era in both our lives. For almost one year, my Mom and I used our twenty-year-old letters as memory prompts in order to remember ourselves together. Reciprocity, relationality, interrupted presence, space-time, identity, gift, and voice resonated throughout that year. The letters sometimes elicited profound engagement, as I had hoped they would, but occasionally—sometimes because of their epistolary nature and sometimes for other reasons entirely—they failed to bridge the unfamiliar distances opening up between my mother and me.

Gaps, Absence, Lapses, Lacunae

If my early letters betrayed my extreme homesickness, my mother’s letters reflected an acute sense of loss. “This morning, August 26 [1986],” she wrote in her second letter, “I went to U of Winnipeg to pay my registration fee and so on. Since I was downtown I picked up another ball of that purple wool in order to finish the sweater you were knitting for me. I didn’t have much heart for knitting lately; I still have to get used to you being all the way in Africa and then I can’t knit right away. That doesn’t make much sense, perhaps; I know I’ll get back into it in a little while.” My mother frames our separation in space and time as the reason she cannot access the usually intense, embodied pleasure she takes in knitting. I will not know this, though, until September 19 when Mom’s letter reaches me. By September 19, however, I will have written to my parents, my siblings, and my grandmother eight times, and I will have tasked numerous friends to make additional connections. “Could you let [my mother] know that I’m definitely not sick anymore?” I write on August 19 to a close friend shortly after reaching Nairobi (Letter #1 to Tracey), and on August 29, I end a long letter to another close friend with a similar request (Letter #1 to Nathaniel). Six days afterward, on September 5, I confide to a third friend that I sometimes worry about how much my mother may be worrying about me. “If you think of it,” I suggest, “you might surprise her with a call” (Letter #2 to Sharon).  

Mom’s early letters and my own are suffused by our shared desire for reciprocity. “Write soon,” Mom implores me multiple times in both her first and her second letter, guessing but not yet knowing how excruciatingly lonely I am at Ndejje. At Ndejje, meanwhile, I am urging her to “write often or I’ll feel too far away” (Letter #2 to Mom and Dad, August 21, 1986) and, pathetically, one week later, “I feel a terrible need to believe that you miss me and are thinking of me the
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way I miss you and think of you” (Letter #6 to Mom and Dad, August 28, 1986). On September 7, Mom begins her third letter with the news of the week: “We’ve received your first letter,” she writes, meaning the letter I wrote on August 16, on the flight to Nairobi. But I will not get Mom’s letter letting me know that my first letter has arrived until October 3, while I am finishing my tenth letter to her. My mother and I wrote constantly because we wanted connection, but a closer look at our correspondence reveals that connection to have been an exchange of constantly scrambled messages, messages confused in and by space and time, messages that constantly gestured toward, but only rarely achieved, direct communication. Our correspondence is an extreme form of what Antje Richter calls a “staggered type of communication,” which is characterized throughout by acute “temporal polyvalence.” And those were the letters that arrived.

On average, my letters to Canada took about two weeks to reach their destinations. Letters sent to me typically spent three or more weeks in transit, but some arrived months after they had been posted and some were late by over a year. A small handful arrived stamped with glorious excuses: “Missent to Manila,” or “Missent to Jakarta,” and once, most thrillingly, “Missent to Funafuti.” Because my regular correspondents and I numbered our letters, I was able to determine later that all my letters reached their intended recipients. At least one-sixth of the letters sent to me, however, failed to arrive. “[L]etters,” says Altman, as if she were speaking to the point, “are both permanent words and losable words.” When the final tally was in, I knew that sixteen of my mother’s 105 letters were gone forever.

In 2007, when I begin re-reading my correspondence with my mother from twenty years in the past, I am struck by the ways it accidentally mimics Alzheimer’s, with its gaps and its weird delays, its distortions of memory and time’s passage, its irretrievable losses. Later in the project, after I have read more broadly, Cardell and Haggis’ methodological questions about the letter and the epistolarium resonate. “Do we recognize the letters that are not there?” Cardell and Haggis ask; and, “If so, how do we deal with the epistolary presences of the ‘not there’?” Later yet, I will read Margaretta Jolly describing Liz Stanley’s work as focused on “the unsaid and lost as well as the saved and said,” and I will be reminded, again, of the irony of using a letter archive this full of holes in a project aimed at restoring and re-storying my mother and me. But that is not until later.

In the summer of 2007, I am, in equal parts, anxious, keen, and full of hope. “Mom,” I say, broaching the project, “Shall we read the letters we wrote while I was in Uganda and see what that helps us remember?” Mom’s quick agreement spurs my optimism. We have always deeply enjoyed one another’s company, and she appreciates the long afternoons I spend with her now, focused on her life. “I’ll have to record our visits,” I explain, “or I’ll never remember everything we say.” The archive may be littered with absence, but the letters remain, unarguably, an unparalleled source of my mother’s history and mine. I am about to learn, though, just how difficult it is to read letters after the fact, with their built-in barriers: the peculiar present tense of a letter’s first-person “voice,” the very specific relationship between a letter’s “I” and its second-person addressee, and, of course, letters’ complicated temporality. I worry, too, that Altman, whom I have now read cover to cover, may be correct when she speculates that “[p]ushed to its logical extreme, epistolary discourse would be so relative to its I-you that it would be unintelligible to an outside reader.” And I recognize that Altman’s analysis assumes full cognitive capacity. What happens to letters, I wonder, once Alzheimer’s is in the picture?
Because my project involves human subjects, I complete an ethics application, which is approved and finalized in early 2008. My mother agrees to the project on a fully lucid afternoon in late summer 2007, and she signs the consent form on January 11, 2008, another fully lucid afternoon. When we sit down together to record what we read and remember, though, she often surprises me. “These were letters that I wrote?” she asks sometimes, when I reintroduce the project, or, slightly differently, she asks, “I wrote letters?” At the beginning of one memorable afternoon, she eyed me skeptically and multiplied the emphases: “I wrote letters?” she asked. “To you?” Before it had even officially begun, that is, my project betrayed its origins in desire. I knew that the letters preserved a priceless history of my relationship with my mother, but I realized very quickly that what I had been hoping for was magic. Whatever else the letters can do, I admit very soon after starting, they cannot bring the mother I remember back to me.

Mom and I continue anyway, improvising our way around impediments we have identified and impediments as they arise. By the fall of 2007, Mom is already having a great deal of difficulty reading on her own, and I realize, after several attempts, that I cannot ask her to read the letters I wrote to her. They are too idiosyncratic, too non-linear, too “voiced,” to make sense to a memory that is disappearing. My second letter, for example, quickly stymies Mom. It is written on an oversized postcard, and while my handwriting is tidy and legible, it is tiny and takes up every space that is not used up by the stamp, the airmail sticker, or my parents’ address. “Dear Mum and Dad,” I write, starting in the top-most left corner, “(Aug. 21/86—Kampala, 9:40 pm—I don’t know how much room the stamps will need so I won’t push my luck!) There are so many things to tell you about that I’m afraid I’ll have to flail around a bit and hope you get some kind of connected picture from the bits and pieces I blurt out.” My excitement and urgency are readily discernible two decades on. I cram words around the printing on the postcard, insert information into parentheses, and at one point insert parentheses into parentheses. When I run out of horizontal room on the postcard, I write vertically along the postcard’s midline. The postcard is a perfect instance of what Richter calls “a letter’s peculiar ability to draw attention to itself,” with its “self-referentiality,” its “manifold and recurring references to time, place, and other circumstances of … writing.” By 2007, I need patience to attend to my younger self’s intensity. Mom, for her part, can no longer construct coherent pictures from the “bits and pieces” of other people’s long-ago writing. So we refocus our efforts on the letters she wrote to me, and she looks up from them frequently, saying, “I remember that,” or, “I would never have remembered that if we hadn’t read these letters.” Still, we proceed haltingly. Alzheimer’s is an unpredictable disease, and its effects are notoriously non-linear. I can never guess from one week to the next how Mom will be feeling when I arrive, what she will want to do, what she will be able to do. I learn by trial and error to follow her lead on our afternoons together and only learn later that these are best practices in dementia care. I always arrive with letters at hand, but if Mom is keen to talk about a newspaper article, or a radio program, or a Bible study she has attended, that is where we focus instead.

On one memorable afternoon, Mom met me at the door reciting a Dutch poem she had memorized in preparation for our visit, and we spent all of that week and the next talking about the poem, about how much she loves the poem, about how we might translate the poem into English. Dutch was my mother’s second language, the only official language of the Netherlands when she was growing up, though she spoke Frisian, her first language, at home with her family. “Goede Dood,” the poem Mom has memorized, appears almost exactly halfway through Merijntje Gijzens: Jeugd en Jonge Jaren (Merijntje Gijzens: Youth and Young Years), a 1000+ page coming-of-age novel that Mom repeatedly identifies as the most treasured of all her treasured books. A literal
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translation of the poem’s title renders “Good Death,” but I understand from what my mother explains that it would be more accurate to say “beloved death,” or perhaps “welcome and welcoming death,” or “steadfast and reassuring death.” The poem’s speaker addresses Death as not just an inevitable but a paradoxically enriching, essential element in living, as the element, the presence, the fact without which life would not be worth living. During the weeks when Mom and I discuss the poem, I come to understand its complexity and its existential longing as a startling gift, a glimpse into the radiant melancholy, the passionate, pantheistic, death-embracing visions that have sustained my mother most of her adult life.

Annelieke Driessen, a medical anthropologist specializing in dementia, notes that people with dementias are conventionally assessed and measured in terms of what they can still do, including, repeatedly, whether they still recognize others, a question that Janelle S. Taylor also reflects on extensively. Both researchers argue, on the basis of fieldwork and personal experiences, that these may be the wrong questions entirely, the wrong orientations to take in relation to dementia and certainly in relation to best care for those with dementias. Put into epistolary terms, I have embarked on this project wanting my mother to reciprocate in the ways she did when we were writing letters to one another. Best practices in dementia care, however, urge me to shift my focus, away from what may no longer be possible in order to value and nurture what is—like this invitation of my mother’s on November 30, 2007, to enter the unsettling world of existential Dutch poetry, where she is in her element and I am dependent on her for translation and meaning.

So I arrive each week prepared with letters and prepared to be surprised, training myself to be less curious about what Mom remembers and more curious about what we might discover together because she no longer remembers. And sometimes, on weeks that Alzheimer’s is dormant or dozing, Mom and I carve out hours at a stretch to read letters and reflect on the memories they prompt. The afternoon of February 22, 2008, for instance, is almost magical. In preparation for our visit, I selected my maternal grandmother’s letters. My mother’s mother wrote three letters to me in Uganda, all in the first year I was there, during the time I was most homesick and while my mother was imploring everyone she spoke with to, please, please write to Kathleen. Except for a few English phrases, my grandmother—whom I called Beppe—wrote to me in Frisian, my mother’s mother tongue. Frisian is an older language than either Dutch or German, complete with its own long literary history and still spoken by about four hundred thousand people, most of whom live in Friesland, one of the Netherlands’ twelve provinces, the province from which both my maternal and paternal families originate. I guess, correctly, that Mom will be riveted by her own mother’s words from more than twenty years ago, but she reads hesitantly. Beppe’s cramped, old-fashioned handwriting is a challenge, but Mom also keeps forgetting whether she is supposed to be reading or translating, and she shifts from Frisian to English at every few words. Mom has spent her life wanting to do anything connected to school right—anything that involves reading and writing and learning—and she looks up from the letter repeatedly, wondering if she is doing it correctly. I encourage her to continue in whatever way she feels most comfortable: Frisian was my first language, too, and I follow my mother’s shifts with ease.

Beppe writes for the first time on September 24, 1986, almost exactly one month after I have arrived at Ndejje. Beppe begins by thanking me for writing to her, reiterating some of what I have written, and explaining that my descriptions of life in Uganda have put her in mind of her own immigration experience in the early 1950s. I have known all my life that my Beppe’s immigration experience was not a happy one, and she underscores it here by writing it out in English: “I nearly died of homesickness!” I guess that Beppe used English to ensure that I would not misunderstand her, but what she omits from her letter—and what my
mother promptly adds—is that if Beppe had died of homesickness, it would have been at her own hand. And then my mother retells a story I have heard before but understand more deeply now. My mother was 16 when her family emigrated. If they had stayed in the Netherlands, she would have begun the post-secondary studies that she longed for, training to become a teacher of languages. Instead, the girl who would later be my mother was obliged to come to strange, cold Canada, where she spent almost a year on suicide watch, ensuring that her mother did not follow through on what she threatened, to throw herself into the frigid river racing past their first Canadian home. So, it was what my grandmother had not written that prompted my mother’s deepest musings, on the regrets, the constraints, and the unfulfilled dreams of immigration. “Sometimes,” Mom says, when I ask her what she is thinking, “I think it never should’ve happened. I really do. The whole thing.” “Do you mean emigration?” I ask. “Jah,” Mom says, “It never should’ve happened.” And then she pauses. “Well, anyway,” she adds resignedly, contradicting every impulse that drives this memory project of mine, “you can’t go back in life.”

My grandmother’s second letter prompted sweeter memories. Writing me again just two weeks later, on October 9, 1986, Beppe reflects again on my situation in Uganda in terms of her own experiences, but this time she goes all the way back to a golden age, several years before she married, when she lived independently and studied and then worked as a nurse. Beppe writes about the inevitability, in unfamiliar circumstances, of an adjustment period, but, she concludes enthusiastically, “it is ien fen de moaiste tiiden yn myn libben west.” “It was one of the loveliest times of my life.” This, too, is a crucial part of our family mythology, the bliss with which my grandmother recalled her work as a nurse. “Beppe should never have married,” my mother and each of her sisters have told me on different occasions; my mother tells me again on this afternoon of remembering: “Beppe should have spent her life with her friends from nursing school. The three of them should have just lived together.”

On this particular afternoon, Beppe’s writing prompts Mom to add a shocking story I have not heard before, about one of my grandmother’s beloved nursing colleagues. Mom and I muse somberly on the events she recounts and then I ease her toward less traumatic topics. About ten minutes later, though, she suddenly veers back, entirely of her own volition, recalling a story about Rina, Beppe’s other especially close friend. This, by contrast, is a funny story, and it is a story Mom adores because it hinges on wit and wordplay, in this case, wit and wordplay in Dutch. “She was visiting a lady,” Mom says of her mother’s friend Rina, “a lady in an old folks’ home, and that lady, that woman said to her, ‘Sla mij maar dood!’” (A rough translation, which attempts to capture both the meaning and the comedy of the syncopation might be: “Just hit me already, hard enough to kill me!”) Mom switches from animated Dutch back to English to explain, “Because the lady, the woman didn’t any longer want to live.” And now Mom laughs helplessly, anticipating the excellent joke. “And then Rina,” she explains, “who was the care woman, said”—and here Mom shifts back to Dutch, taking on the voice of a seasoned nurse, someone who has seen it all before: “‘Ja, dat dach je maar: jij lekker in de hemel, en ik levenslang in de gevangenis!’”

I am exhilarated to realize that I still know enough Dutch to get the joke’s caustic play with linguistic and existential possibilities. “Sure,” Rina might have said if she’d been speaking English, “you go ahead and imagine that: you nicely in heaven” [by implication, “for all of eternity”] “and me in prison for the rest of my life!” “I’ve always found that so hilarious,” Mom says when we finally catch our breaths, and then she adds, “I’m lucky. That’s one of the things I remember. I don’t remember what I did ten minutes ago, but that I remember!”

Kathleen Venema
In “The Epistolary Gift, the Editorial Third-Party, Counter-Epistolaria: Rethinking the Epistolarium,” Liz Stanley describes epistolary writing as a form of gift exchange, which, she says, “involves the circulation and symbolic gifting of relationships—the reciprocity of correspondences. There is the gift of the letter itself,” she elaborates, “but more importantly, there is what it metonymically stands for and symbolises about the ongoing social bond between writer-giver and addressee-receiver”; Stanley goes on to describe the process as circulatory, proposing that “its in-built extension to third-party relationships produces continuous flows and multifaceted networks, in which the hope or expectation of response comes to take on an obligatory and constraining character.”

Like Stanley’s multifaceted networks, the project of reading and remembering and discovering with my mother extends again and again to third parties, long-ago relationships, almost forgotten friendships. On October 9, 1986, the same day that my grandmother writes her second letter to me, I begin my eleventh letter to my parents using a beautiful greeting card, and I comment that I bought the card while I was shopping for a friend’s wedding, someone I name, someone my parents know. Several paragraphs on, I assure my parents that I am eating well, unlike a former aid worker whom we had met before I left, who had lived in Uganda throughout the war and described the spartan menu to which she had been limited. Most telling of my dependence on epistolary networks, I reference a car accident that I have been in but breezily offer few details, assuring my parents that I have described the events twice already, in long letters to one of my close friends and to one of my mother’s sisters, both of whom—I assure my parents—have been instructed to telephone when those letters arrive.

The project itself is multifaceted in ways that often exceed my managerial abilities. There is the work of organizing the letters, the work of transcribing the letters, the work of finding reliable transcribers when I realize I cannot do all the transcribing myself. When the transcribers begin to send in their work, I realize how much easier typescript is to read than handwriting, and I do not know whether to regret the time Mom and I have spent deciphering originals. There is the work of recording our weekly conversations and the time-consuming work of transcribing our conversations, all while teaching full time, researching dementia care, and trying to keep up with the demands of actual dementia care. Throughout all the kinds of work, I continue to reel, emotionally, every day, at the realization that my mother has Alzheimer’s and she cannot be cured. And I am struck repeatedly, as I dive deeper into this memory project, by what I have remembered about my three years in Uganda, what I have misremembered, and what I have forgotten completely.

I discover that while I can tell extended versions of pivotal events at Ndejje, I have written about them in bits and pieces—early versions to one recipient, additional details to another, final episodes complete with punchlines to a third. I am disappointed by how few of the letters are self-contained narratives because it is these scattered bits and pieces that make letters so difficult to comprehend after the fact. I discover that I have remembered accurately the unexploded landmine on the college campus, the anxiety of being assigned to teach Ugandan agriculture, and the thrill when I have learned all my students’ names, but I have forgotten my determination to learn Luganda and how I would practice in my letters home. I have remembered accurately the timeframe during which I began experiencing the first mild symptoms of what would later become a serious illness, but I have forgotten how hard I worked to keep the worst details from my parents. And I discover with some surprise how much of my mother’s time and energy during those years were spent looking after her own mother.
My mother was not close to her mother the way she and I were close, but Mom was diligent in her care for Beppe, adhering dutifully to the schedule that she and her siblings had drawn up to meet their mother’s needs. Because Beppe’s apartment was less than three kilometers from my parents’ home, my mother was almost always the first of her siblings on the scene in cases of grocery shortages, unscheduled outings, big and small emergencies alike. Questions of best care for Beppe emerge repeatedly in my mother’s letters, I discover, and I am struck by the resonances, as I struggle every week to determine how best to care for my own mother now. On March 28, 2008, about a month after we read Beppe’s letters, I arrive at my parents’ home with my mother’s 41st, 42nd, and 43rd letters. Mom’s Letter #41 includes some of her responses to my first descriptions of illness, but in Letter #42, she writes about my grandmother’s alcoholism. Sometime after my grandfather’s death in 1972, Beppe began to drink to ease the pain of loneliness. Sometime during the next decade, it got to be a habit. Until I had unearthed the letters, I had forgotten completely. Mom writes on August 9, 1987, the day after we had managed to have a brief telephone conversation:

From our conversation yesterday I realize I must have written something about Beppe, but I can’t quite remember what. In any case, I’ll expand a bit, so you won’t worry about her unnecessarily (spelling?). As you know, she’s liked her drink for a long time already, certainly since before Pake died. Over the years as her arthritis and deafness became worse and her isolation increased and her dependence on others, she began to drink more, and more often and certainly the last 5 years (and maybe longer) she put away at least two 26 ounce bottles of whisky per week. Eta bought one for her every Thursday after they’d been out for brunch, but unbeknownst to Eta, Louis bought her another on Fridays when he did her grocery shopping. (And Louis didn’t know about “Eta’s bottle”.)(Letter #42 from Mom and Dad)

On March 28, 2008, Mom and I are aghast at the quantities. Two twenty-six-ounce bottles in a week? “Whisky?” Mom asks, deciphering her own handwriting. “Did Beppe drink whisky?!” And she chuckles as Beppe’s scheme reveals itself: the bottle my aunt bought for her on Thursdays after their weekly brunch; the bottle my uncle brought over with the groceries on Saturdays. “Beppe had quite a scam going, didn’t she?” I say and we explode with laughter. “Holy Dinah,” Mom muses, subdued by the time she has read to the end of the section. “Now that I read it of course I remember. And I remember that I found her fallen off her bed, you know. I remember that, and of course, I was the nearest daughter. Holy Dinah,” Mom repeats, and then she switches to Frisian. “Achhhhh,” she begins, an untranslatable expression of compassion, “I feel so sorry for her even now. Poor soul. She was so homesick.”

Altman writes about the letter as an “instrument of revelation and discovery” and the ways in which “the act of reading in epistolary fiction often corresponds to the classical moment of recognition.” I’m intrigued on this afternoon by the way that re-reading her decades-old letter prompts Mom to an encompassing compassion for her mother, for the loneliness she now recognizes as suffusing her own mother’s life. Mom’s compassion strikes me forcefully that afternoon because it expresses a quality and depth of empathy that she rarely accessed while Beppe was alive. And then our conversation morphs, away from the letter, to speculations about how Beppe might have found alternatives to her loneliness, how Mom is dealing with her own loneliness, how awkward and nervous Mom finds herself now in conversations even with old friends, how she feels most comfortable when she attends meetings at the Alzheimer Society because, she says, “We’re all the same; we don’t have to hide it; everybody knows we’re forgetting stuff!”
We laugh as we do so much of the time, but Mom’s insight into Beppe’s loneliness provides me an insight into hers. My mother was an introvert and notably reserved all her life. She had a few close friends from university, she had her six buoyant sisters, she had me, and she had a talent for making friends with my friends. On returning to our letters, I had been struck many times by how frequently they reference my friends, how frequently one or another of my friends contacted my mother while I was in Uganda. So on my next visit, I deliberately arrive with Mom’s 43rd letter again, which I am eager to read because it begins with the visit Mom had had just the day before with one of my friends. “Shannon took me out for lunch yesterday, to a place in Osborne Village,” Mom announces enthusiastically on August 18, 1987, after assuring me that my letters have continued to arrive, “(Osborne Village Inn, it’s called, I think …) it’s a neat place, and I had ‘blintzes’ for the first time in my life.”

I have deliberately brought this letter again because I want to remember out loud with Mom how gallantly my closest friends worked to fill the gap of my absence. “Before you left,” Mom muses, after adding details about her lunch with Shannon, “I could always count on you to take me out. Now it’s catch as [catch] can. But,” she adds reassuringly, “that is not the only reason why I miss you.” This is what I specifically wanted to get to, and when we read the letter 21 years later, I try repeatedly to prompt memories of this sweetness. “Do you remember how we’d sit and talk over lunch Mom,” I ask her, “all those little places we’d go to in Osborne Village?” Mom tries to say, “Osborne Village,” at the time a popular restaurant district in Winnipeg, but she struggles with the consonants and shakes her head. “Do you remember our lunches,” I ask, and she answers valiantly, “Vaguely.” What Mom remembers, as we talk, is that “The ladies, the ladies I worked for, didn’t they live in Osborne Village?” For about five years, beginning in the early 1970s, my mother cleaned house for three older women, all of whom lived in the Osborne area. Because these are the memories the letter has prompted, we take our time on this afternoon together to remember each one of “the ladies” in as much detail as we can. And when it seems we have assembled as many details as possible, I ask, “Mom, when you wrote me this letter, you hadn’t worked for the ladies for more than ten years. Do you have a clearer recollection of that than of the time I was in Uganda?”

Mom considers the question a long time and her answer is startling for its insight. “In a way,” she says, hesitantly, because she doesn’t want to hurt my feelings, “yes. Because it has more to do with your body than your thought processes. When you were in Uganda, there wasn’t a lot I could do except think of you. And a thought,” she says, “you cannot conjure. But a thing you can think of. … If you arrive to clean someone’s house and then you drive back home—you can see that in your head: ‘now I was there and now I’m going there.’” And then my mother tells me again the poignant thing she has begun to tell me during this first winter of conversation: “You have no idea what I’ve forgotten. You have no idea how much I’ve forgotten.”

**Remembering Forgetting**

It is tempting to underscore the uncanniness of my mother’s experience, the way she seems to simultaneously both forget and remember forgetting, and it is tempting to imagine that this uncanniness is somehow unique to people with Alzheimer’s. It is worth asking, though, as some researchers and activists do, why we hold people with dementia to such high standards. And it is worth remembering, as those researchers prompt us to do, to contextualize the uncanniness of dementia within a framework that acknowledges the frailties of our own “normal” minds.
Kathleen Venema

On Friday April 25, 2008, two weeks after my conversation with Mom about “the ladies,” I am more than usually flustered and under-prepared. I have not yet chosen letters for today’s visit, so I simply pick from the top of a stack of typed transcriptions as I dash. Once on the bus, I realize these are Mom’s first two letters, and I marvel that I have not yet thought to bring them. Before Mom and I begin reading later that afternoon, I ask her what she remembers about the summer I left for Uganda. Mom is alert this afternoon and eager to engage. “Didn’t we take you to the airport?” she asks. “Weren’t some of your friends there?” They were, five of them, hilarious, disbelieving, none of us able to imagine three years without one another. Mom and I enjoy the memory, but it is painful to see how hard she has to work to remember my friends’ names, despite the efforts each one of them made to stay in touch. And then we turn to Mom’s first letter:

I had a call this morning at 9 am from MCC to inform me that they had received a telex from Nairobi to inform us that you had arrived safely and everything was going well, which I was very glad to receive of course. Dad had suggested that I start keeping a diary, … so I bought a smallish notebook and have scribbled in it a few things every day…. I think I mentioned to you on the phone that Kim called, that I gave her your address and that she will be teaching in Baldur, MB, grades 5 and 6, I believe. … On Tuesday, August 12th, I took Beppe to her hairdresser’s for a perm…. While she was there I went to visit Annie, where it was bedlam as usual, but then, I guess it’s no wonder with three foster children and three of her own…. Later in the evening I had a long telephone conversation with Sandy. She told me all about her work. She had been to Stony Mountain Penitentiary to interview two inmates, which was quite interesting. … Saturday we had the two weddings to go to as you may recall. The ceremony in Calvary Temple was not very long and a large part of it seemed to be devoted to the show of the entrance of the various attendants and the bride herself who was not “given away” by either her father … nor by her grandfather. Annette walked into the church alone, for which she has my respect. I don’t think that is the usual thing to do in their circle. (Letter #1 from Mom and Dad, August 18, 1986)

Our afternoon of reading and remembering, on April 25, 2008, proceeds with a distinct measure of success. “Who is Kim?” Mom has asked, when she reads that “Kim called,” and promptly asks, “Where is Baldur?” when she reads where Kim will be teaching. Mom has to work to remember that “MB” is the abbreviation for Manitoba, puzzles briefly over who Annie might be (with all the foster children and “bedlam as usual”), but she pronounces “penitentiary” perfectly when she reads about my sister’s articling work for her law degree. Mom is stumped, though, when we reach the description of the two weddings that she and Dad had attended. “Annette walked into the church alone,” Mom repeats several times, gathers enough momentum to finish the sentence—“for which she has my respect”—then looks up and asks, “Why did Annette walk into the church alone?” It is a marker of Mom’s cognitive loss that she no longer remembers that in some wedding traditions, fathers “give their daughters away,” a further indicator that she no longer remembers the vehemence with which she once deplored the tradition. But it takes just a few moments of conversation before Mom declares, “So it means, ‘Now I’m rid of her and now you own her’!? Good grief, it sounds like slavery.” She pauses and then reflects with considerable humor, “So I said that already then, eh?” She pauses again and adds, “Well, you know me. I was pretty sharp in those days with my pronouncements! Pretty harsh in my judgments.” She pauses one more time, unrepentant. “I still am,” she says, and we both laugh.

It is a delightful afternoon, not only because of Mom’s pleasure at discovering resonances with her earlier self’s strongly-held opinions. I will not have time, though, to transcribe our conversation for over a year. I have learned that while I can hire people to help transcribe the letters,
I have to transcribe the conversations myself. I am the only one who can consistently make out what Mom is saying, especially when she switches amongst languages, the only one who can guess accurately at what she is trying to say when she struggles for words, the only one who can decipher what we are talking about when our words overlap or get lost in laughter. Besides, Mom and I sometimes speak candidly, and I need to be able to protect her privacy and the privacy of people she speaks about. But the work of transcribing is painfully slow. Over the years and on different devices, I record more than 150 conversations with my mother, each, on average, two hours long. Extrapolating from shorter experiments, I determine that it takes about eight hours to render an accurate word-for-word, pause-for-pause transcription of a two-hour conversation. That includes time to record the details as Mom switches amongst languages and to spell correctly in languages I have never formally learned to read. My husband urges me to try a word-recognition program, but I look askance. What on earth would such a program make of intermittent Frisian, Dutch, and German, and Mom’s multiple attempts to pronounce tricky syllables in English?

In mid-December 2009, I block out several days to review and add to my collection of first-draft transcriptions, and I observe, again, the multiple levels at which this project exemplifies epistolary writing’s unique ability to “portray the experience of reading.” Yes, I think: reading and then re-reading, recording the re-reading, transcribing the recordings, and reading the transcripts. I am deep into the ontological complexities that Stanley describes in her article on epistolary gifts, though the article will not be published for several years.

On the second day of my transcribing marathon, I select the recording of our third official visit, January 25, 2008, because that was the first time Mom and I officially read letters to one another. I want to remember our exact words. Headphones adjusted, document open at the precise spot that the manuscript begins, I prepare to amend at top speed and press “play.” Nine minutes in, I stop typing, hit “pause,” and peer at the details I have just added:

Mom: So where am I now? [pause] Oh. Mmmmmm. “Tuesday August 12. I took Beppe”—that’s Mom of course—“to her hairdresser. While she was there, I went to visit Annie, where it was bedlam as usual.” [pause] Annie? Who would that have been?

Me: Who would that be, Mom, Annie?

Mom: [pause] Annie Venema of course!

I re-read what I have edited so far and review what I drafted the first time through. Mom is reading from her first letter, and it is all there, or mostly there and mostly in the correct order: Nairobi, telex, Dad, diary, notebook. Kim, Baldur, Sandy, Stony Mountain, penitentiary (tackled three times, then pronounced perfectly). Beppe, bedlam, foster children, and misogynist undertones in wedding rituals that require fathers to give their daughters away. “I was already pretty blunt then!” Mom says on the recording of our January 25, 2008, visit, admiring, half-embarrassed, mostly pleased to remember her spritely, opinionated younger self.

But I am baffled. I have just read this exact conversation somewhere else. I scrabble through the documents I have been creating and refining. Here it is, the transcript for April 25, 2008. I was just looking at this. Mom and I are reading a typed version of her first two letters to me because handwriting is so hard to decipher. This happened exactly three months after the conversation I have just been reviewing and rendered a transcript implausibly similar and frequently eerily exact. Uncannily exact. Word for word, pause for pause, puzzled question for puzzled question, Mom and I had almost exactly the same conversation on the twenty-fifth day of both January
and April 2008, and neither of us remembered. “Oh my goodness,” I type slowly into the middle of the January transcript, “this is so weird.”

And only now, as if this were a letter that had been posted in the best of faith but accidentally misrouted to Manila or Marseille or Melbourne and therefore very late arriving, I add missing and necessary information. On February 22, 2008, the same afternoon that Mom and I read Beppe’s letters with so much pleasure, doctors discovered that my baby nephew, Harry, had an exceptionally rare form of liver cancer. Ten-month-old Harry was my parents’ only grandson. For the next six months, baby Harry’s urgent journey with cancer overshadowed any other story our family might tell. My husband and I took on various roles as soon as we heard the news, helping to organize hospital visits and meal donations, setting up a blog to keep family and friends informed, supporting my parents emotionally. Every moment of our days was inflected by Harry’s illness: the stomach-churning wait for a precise diagnosis, the numbing details of carefully calculated chemotherapy, the need to get accurate updates to everyone in our widening circles of support. Every visit with my parents was suffused with concern about Harry, and then, as the weeks passed, cautious, breath-held optimism when Harry responded well—better than anyone could have predicted or imagined—to his first, his second, his third round of chemo.

I was grateful to be on a research leave, but I was always scrambling, including on the morning of April 25, 2008, when I laid my hands on the first letters I could find as I dashed for the bus, the typewritten letters at the top of the stack on my desk. I was late that morning because my sister-in-law had called from the hospital just as I was leaving, with an update on Harry’s progress, and I needed to make careful notes to ensure that my next blog post would be accurate. Mom and I read her first letters for the first time on January 25, 2008, in a world that seems idyllic now, because in that world we had no reason to believe that baby Harry was not perfectly healthy. Exactly three months later, on April 25, 2008, we read a typescript of the same letters in the shadow of Harry’s cancer and neither of us remembered our afternoon together in January. It is important to me to remind myself that I do not have Alzheimer’s but my mother and I both forgot that we read the same letters twice and had almost exactly the same conversation about them both times.

Harry was so healthy when his sixth round of chemo began that we fervently believed he would qualify for a liver transplant soon. The CT scan the day after chemo ended staggered us with its news. The cancer had not just returned but spread itself throughout Harry’s liver and re-entered his lymph nodes and both of his lungs. Harry’s heartbroken medical team discharged him to his parents on July 18, 2008, with a palliative program. Two weeks and two days later, Harry died. Months afterward, my shattered family began resuming some of our routines, including my weekly visits to my parents, but on the first, and then the second, and again on the third attempt to read letters with my mother, the results were gibberish and incomprehension.

After Harry died, I was not able, ever again, to read letters with my mother. It was certainly because of Alzheimer’s ongoing deteriorations, but it was also because of grief that my mother was suddenly unable to do the extra cognitive work that letter reading requires. Margaret Lock, a medical anthropologist who examines how mind, body, and environment are entangled in any individual’s life course, sketches a plausible explanation. Lock is clear that “mind” cannot cause “the terrible neurological devastation of A[lzheimer’s] D[isease],” but she is equally clear that “mind as consciousness,” which she understands as involving both shared social life, and, at times, enormous trauma, “can undoubtedly make an indirect contribution to neuropathology.” In 2008, in the wake of my nephew’s death, the abrupt end of letter reading with my mother left me doubly bereft. For a very long time, I imagined that the epistolary aspects of the project had failed, ending almost before they had begun. By now, though, I treasure every moment of our attempts, every
Letters as Memory Prompts in Dementia Care

memory of the afternoons that Mom and I read our old letters and of what the letters prompted us to remember and to discover, and of all the laughter we managed before the letters ran out. Every one of our letters was a gift when we exchanged them throughout the mid-1980s over thousands of kilometers’ distance. Twenty years later, in the face of dementia’s erosions, and if only for a while, they brought us the gift of togetherness and a surprising amount of joy.

Conclusion: The Gifts of Even Imperfect Correspondence

Mom and I first discovered the immense pleasure of talking together about literature in the mid-1970s, when she began reading the novels I was bringing home from my high school English classes. Thirty years later, facing Alzheimer’s, I knew that our memory project would involve as much reading out loud as possible, and as much talking as possible about what we were reading. My fondest hope was that our reading would encompass the 200+ letters we had exchanged in the 1980s while I was living in Uganda and my mother was completing her undergraduate degree. I imagined those letters, from a vital time in both our lives, as a kind of portal, one that would take us back, together, into our shared past. Letters, though, are difficult to read after the fact, more difficult yet when dementia is at play. Alzheimer’s disease works at its own erratic pace, and I learned repeatedly to let go of my plans and follow my mother’s lead on the afternoons that she wanted to do and talk about something else entirely.

But the letter reading that Mom and I managed, and the memories and discoveries that our reading prompted, intensified our already rich connection to one another. When I look back on our project now, moreover, I see its deep rootedness in reciprocity and relationality—not coincidentally core features of the epistolary genre. In an ideal world, the project would have begun when Mom still understood much more of what she was reading. In an ideal world, we would have had typed transcripts of the letters at our disposal, with strong narrative passages excerpted and contextualized. But there would be no Alzheimer’s in an ideal world as there was in ours, and so I am glad I learned in time to stay flexible, open to Mom’s directions, including on all the afternoons when she asked, after we had finished eating lunch: “Are we reading letters today?”

More than four years after Harry’s death and just two months before we admit my mother into permanent care, letters make one last appearance in our memory project. By November 2012, I could borrow Stanley’s wonderful term “interrupted presence” to describe every day that I spend with my mother. By now, our activities and games are so much diminished from what they once were that I often simply dream up words and ask Mom what they mean. My mother is not who she once was, but our delight in language play goes on, evidence, as Lynn Casteel Harper assures me, that my mother is not “gone.” Even this deep into dementia’s waters, my mother is palpably real, as real as I was in 1986, despite my fears and the 13,000 kilometers that separated me from everyone I had known. On our afternoon together in 2012, the word “enterprise” makes Mom too anxious to answer, so I quickly propose “vacillate” instead. Mom tackles “vacillate” after a long, thought-filled pause, and though her definition is garbled, I understand some parts of it and assure her that she is absolutely correct. When I propose “correspondence” next, Mom answers without hesitation. “Correspondence,” she says confidently. “That is when—say you have something and then something else. And you have something, and you say, that looks like the same thing.” I tell her that she is exactly right, that if one thing corresponds with another, it means the two things are
quite a lot alike.” “Jah,” Mom says, “and then if, say, you are living here and someone else is living there, and if you want to communicate with them, maybe you send them something, like a message.” I am amazed. Even now, more than seven years after the Alzheimer’s diagnosis, Mom can still conjure both main meanings of “correspondence.” I tell her again that she is exactly right, that that is exactly what “correspondence” means. I praise her enthusiastically. I am thrilled to see her happy and to make her happy. And then I say, “Do you know Mom, when I lived in Uganda, we would send each other letters. We wrote each other letters every week and those letters were our correspondence.” And now Mom dazzles me with a smile. “We did, eh?” she says. “That’s good.”

NOTES

1 Janet Gurkin Altman, Epistolarity: Approaches to a Form (Columbus: Ohio State University Press, 1982), 119.
2 During the 1980s when I wrote these letters, I spelled the word I called my mother “Mum,” though my mother always signed herself “Mom.” For several decades now, I have used the latter spelling to refer to her.
4 On the advice of experienced development workers, my regular correspondents and I all numbered our letters, so that we would always know when letters arrived out of sequence or when letters were lost. Numbered, the letters were easier to organize chronologically when I returned to Canada. My informal archive comprises two file boxes filled with manila folders, each of which contains a collection of letters and is labelled either, “Letters to [name]” or “Letters from [name].” In some cases, the folders also indicate the letter-range (e.g., “Letters from Mom and Dad #1-30”). I kept detailed notes in my journal of when I posted letters and when I received letters, which made it easier, later, to determine how long specific letters had spent in transit.
6 For example, from Naomi Feil and Vicki de Klerk-Rubin, The Validation Breakthrough: Simple Techniques for Communicating with People with “Alzheimer’s-Type Dementia,” 2nd ed. (Baltimore: Health Professions Press, 2002).
8 The completed project was published as Bird-Bent Grass: A Memoir, in Pieces (Waterloo: Wilfrid Laurier University Press, 2018).
9 It continues to be difficult to pinpoint the origins of dementia’s processes, but it is likely that damage to the brain starts a decade or more before cognitive problems appear. If that is the case, even the last of Mom’s letters, the ones from June 1989, were written before she began experiencing the first early symptoms of Alzheimer’s. “Symptoms and Diagnosis of Alzheimer’s Disease,” National Institute on Aging. https://www.nia.nih.gov/health/what-are-signs-alzheimers-disease, accessed May 16, 2017.
10 Some names in this article have been changed.
11 Antje Richter uses the terms “dialogicity” or “reciprocity” to denote textual features that reflect “a writer’s sustained efforts to engage a specific, usually absent addressee.” “Literary Criticism in the Epistolary Mode,” The Journal of Epistolary Studies 1.1 (Fall 2019), 9.
12 Richter, “Literary Criticism,” 9; Altman uses the term “temporal polyvalence” to describe the fact that any epistolary statement is always relative to multiple and sometimes multiplying moments in time: “the actual time that an act
described is performed; the moment when it is written down; the respective times that the letter is despatched, received, read, or reread” (Epistolarity, 118).
13 Altman, Epistolarity, 135.
14 Cardell and Haggis, “Contemporary Perspectives,” 130.
16 Altman, Epistolarity, 117.
17 Altman, Epistolarity, 120.
20 I do not know when my mother would first have read A. M. de Jong’s novel, originally published in 1925. Her copy bears the copyright date 1977, when she would have been 41 years old.
22 I would like to extend my heartfelt thanks to both of the anonymous readers of this article for their warm encouragement and for the suggestion that I make more explicit the extent to which my work with my mother was frequently a process of discovery rather than a process of remembering.
23 In addition to Frisian and Dutch, my mother spoke English, German, and French, learning the latter three languages at school beginning in what would have been the equivalent of Grade 7 in Canada. In 1988, she graduated from the University of Winnipeg with a Bachelor of Arts degree, having majored in French.
25 “Pake” is the Frisian word for “grandfather.” My mother and her siblings frequently referred to their parents as “Beppe” and “Pake.”
26 Altman, Epistolarity, 92.
29 MCC is the Mennonite Central Committee, the organization for which I was volunteering.
30 Altman, Epistolarity, 88.
31 Stanley, “Epistolary Gift,” 141–44.
33 Stanley uses the phrase to describe what it is that catalyzes or produces ordinary letter writing (“Death of the Letter,” 243).