

OUT OF TIME

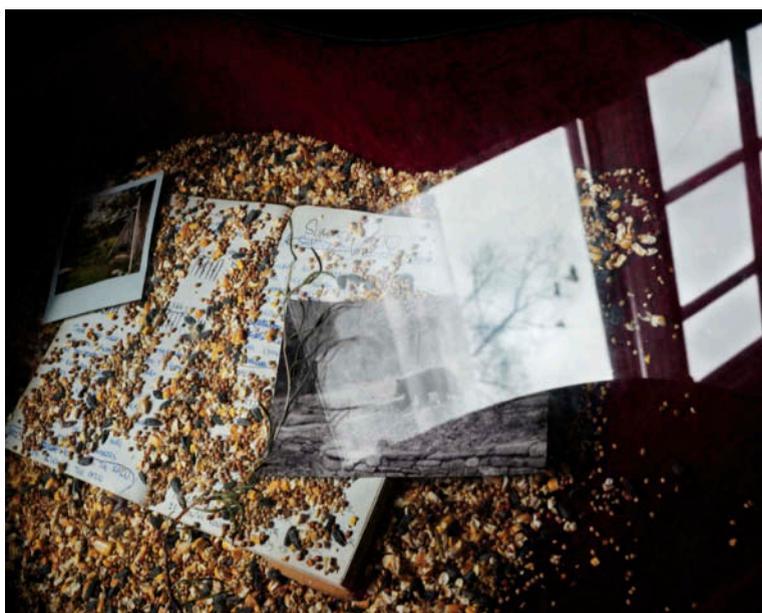
The un-becoming of self
By Sallie Tisdale

We all know dementia by now: the organ of the brain breaking down in substance and function much as a heart or liver does. By the time a person dies from complications of Alzheimer's disease, his or her brain is significantly smaller than its normal size. There are several major variants of this process, and the disorder's progress takes many forms: insidious, incremental, dramatic, fast, and slow. The biology of loss is complicated and not entirely predictable; but in every case, memory, language, and motor control eventually slip away until a person finally sinks into silence and immobility. One could write volumes on the meaning of this gradual dissolving of a person—mustn't it mean something?

I am used to the cuckoo's-nest world of locked memory-care units, to looping, opaque conversations. I work as a visiting nurse for a palliative care agency; the majority of our clients have dementia and live with family, or in assisted living facilities or nursing homes. The world

Sallie Tisdale's most recent essay for Harper's Magazine, "Miracles and Wonders," appeared in the November 2015 issue.

that I see is far more nuanced than the commentary surrounding it: there is grace here, rare intimacy, moments of startling clarity—and, yes, happiness. If slowly disappearing is a disaster, is the



abrupt tsunami better? The stark fact is that dementia is incurable, progressive, and fatal, but here is the surprise: in the company of the demented, one finds peace and unquestioned love in at least as much measure as in the rest of the world. I watch my clients navigate each day's puzzling details. I know their efforts may look to many observers like an embarrassment of loss. I see the riches: the brave, vulnerable, completely human work of figuring things out. People

with dementia sometimes have a rare entrancement with their surroundings, a simplicity of perception, a sense of wonder. Being with a person who has dementia is not that different from being

with a person who doesn't share your language. It is a little like talking to someone who has lost her tongue and cannot speak, has lost his hands and cannot write. This is not a bad thing; it is just a different thing. It requires a different kind of attention.

Here is Maria, who really shouldn't be living alone anymore, not least because she will let anyone into her apartment.* The hot meals delivered every day pile up until one or the other of her caregivers throws them out. Here is Joe,

who never speaks more than a word or two and watches the world from under hooded, skeptical eyes. Here is Ann, who has a strange gastrointestinal disease, the kind of bodily disruption that would make many of us collapse. Ann does not seem to notice. She scoots her wheelchair about the hallways all day long, talking to passersby, nurses, posters on the wall, plants, and herself with an equal degree of cheer.

*Names have been changed to protect privacy.

Here is Mattie. She has vascular dementia, which can manifest in a dizzying number of ways, depending on where in the brain the damage is—lost executive function, an inability to speak, personality changes, incontinence. Mattie is a petite woman with thick eyeglasses. She is very thin and sleeps a lot, often with her legs spilling off the bed in a sprawl, as though she has fallen there. She loves her husband (who visits every day), her dog (who died some time ago, but she has forgotten that), and milkshakes, her main source of nourishment.

“How are you doing today?” I ask her. She blinks at me. “They take me, take me away, and that takes my sleep away,” she says. “To where the vacuum is.” We walk hand in hand, Mattie moving with the delicate care of the invalid because she has trouble with her balance now, to look at the roses in the garden. She tells me about the roses she used to raise—not, that is, in so many words but in small gestures and slow, stumbling sounds. She grew roses or loved roses or loves these roses, or these roses remind her of something she loves. The difference between the possibilities is not important anymore. I lead her slowly back up the ramp into the living room. She pauses a long time—there are many pauses in the company of the demented—and then notices herself in a mirror: “There she is in that place, and she can’t get out.” She turns and smiles at me and looks away. She is done talking.

Albert looks for his wife. He is always looking for his wife. He staggers into the hallway without his walker for the third time in an hour. He is led to a chair, another fall averted, and the aide brings his walker and tells him that his wife will be arriving soon. He sits in the dining room, banging his walker on the floor like a prisoner banging his tin cup on the communal dining table. “Where’s my wife? I want my wife!” She is coming, I tell him, and he calms down. He is always looking, and she is always coming. I am a witness to Albert’s *now*, the now in which he is looking for his wife and sometimes finds her, and it is unwound into strands that we can (al-

most) name yet has all the quality of the now each of us cherishes.

The philosopher Daniel Dennett calls the self a bowerbird: “It appropriates many found objects which happen to delight it.” Out of its vast collection of stuff, the brain builds the self an autobiography, what Dennett calls a “center of narrative gravity.” Is consciousness a story? Is it story, author, and reader as one? Memory is pocked with gaps at best, prone to falsehood and suggestion; the story changes over time. Is the self like vision? I see only phantoms: my eyes move in tiny jumps called saccades. My visual cortex draws conclusions about what I am seeing, adding context and experience to create a

WHEN WE SAY SHE’S NOT MY
MOTHER ANYMORE, WE MEAN SHE IS
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THE MOTHER WE REMEMBER

smooth snapshot. I am seeing a tree, a dog, you—but not exactly the tree, the dog, or you. Perhaps consciousness is like this, a construct of countless saccadic encounters. We each make of this center of gravity what we will: a pearl of soul, a loosely cohered braid of experience, a voice talking to itself in emptiness. To consider what happens to a person with dementia requires me to consider this bowerbird self, the bounds and limits of all that I consider myself to be. Because the center cannot hold.

When I look at my son, who is almost forty, I sometimes think, “He’s not my baby anymore.” My son does not ever think this way. Children are expected to become altogether new; parents are not supposed to change.

I watch a man watch his mother. She follows the other residents all day long. She is trying to help them, to feed and dress them, push their wheelchairs, put them to bed. She was a homemaker, and now she is doing for others what she did for her son. Sometimes she cries in frustration; her charges are obstinate and resist her care. To her son, the wom-

an is not his mother anymore. It is as though she died and yet remains.

The people closest are always comparing *now* to *then*, *the way she is now* to *the way she used to be*. When we say *She’s not my mother anymore*, we mean she is not the mother she used to be, the mother we remember. One of the mysteries of self (besides the fact that it can’t be located) is that the self is at once both changing and stable. We are descendants of our past selves. I am not the child I was, or even the woman I was a few months ago, but close enough. A hidden through-line pulls us along, my me-ness changing slowly enough that I always seem to be me. Significant brain damage (as with dementia) can leave the personality almost untouched for a long time. When I hear the reaction of the woman’s son (and I hear it often enough), I am reminded of this way in which life is a story. I may not be the same from year to year, but I expect you to be. My autobiography includes you as a character, fixed into a particular part of the story. She was never *just* his mother, but he’s not in the best position to see that. He thinks she has died because she forgot him. She left his story.

The fact that my own me-ness persists is obvious, and yet a persistence of identity is one of the last things we expect with the demented. They seem different to us; mustn’t they be different to themselves? The spate of recent research considering how a person with dementia actually feels tells us no, not really. People know they have a memory impairment, but they feel themselves to be the same person, even in late stages of the disease: “I’m like a slow-motion version of my old self,” says someone with dementia. The possibility of pleasure, let alone contentment, for this person is barely acknowledged. A team of researchers called our current vision of dementia the tragedy discourse. Another group notes that most researchers have shown “a stark disinterest in happiness,” and their assumption of distress is because that is “the only available lexicon for experience, the only available lens through which dementia is viewed.” Surveys have found that Alzheimer’s disease, the most common form of

dementia, and cancer are the diseases that people fear the most. The communal response to dementia seems to invite only existential despair.

When Mattie looks in the mirror, what does she see? Is she commenting in symbolic language about herself, is she able to consider herself only as a character in the story, or does she see a woman behind glass? The neuropsychologist Paul Broks (who reminds us that “the degradation of personality is a neurological commonplace”) believes that people retain a nuanced sense of self even with significant brain damage. We mistake the inability of the self to speak of itself for the absence of the self. When I walk with Mattie, when I chat with Ann, when I calm Albert down because he can’t find his wife, I can only guess what the world looks like—what I look like—to them, who I represent, what I *mean* in their experience. By any objective measure, Mattie is enjoying the garden and Ann is laughing, and even Albert relaxes when I bring him a cup of coffee. Paul Broks, musing about the enigma of selfhood, writes, “The quality—the feel—of our experiences remains forever private. . . . I can’t see a way round this. Privateness is a fundamental constituent of consciousness.” I can project my anxiety about my own threatened self on them, or I can see what’s in front of me and bow to all that can’t be known.

Perhaps dementia has always been with us in one form or another, and perhaps it always will be—an entropic response. People have tried just about anything they can get their hands on to stop it: blood transfusions, digitalis, thyroid treatments, nicotinic acid, massive doses of vitamins, hormones. Papaverine, a nonnarcotic derivative of opium, has had many proponents. A variety of placental, embryonic, and

amniotic extracts, heated seawater, lecithin, naloxone, chelation therapy. The list has a hollow bravado, the names like bycatch in a vast net: coca, amphetamines, heparin, iodine, bircher muesli, royal jelly, hyperbaric oxygen. Intravenous injections of procaine hydrochloride, commonly known as novocaine, were used for a long time. Ergot, a fungus, has its fans; a form of it is still widely used in Europe. Today, a few medications based on acetylcholine can slow the



progress of Alzheimer’s disease and improve so-called problem behavior for a while; the mild improvements are usually not seen for months and are not enduring. Last year, both Merck and Eli Lilly stopped large experimental studies when the drugs did not prove effective.

The enormously costly body of research concerned with dementia is focused first on cure and prevention and then on how best to “manage symptoms.” The existential experience of dementia is almost completely ignored; vanishingly few studies have considered what it is like to *be* demented. The distress with which dementia is viewed creates its own bitter distress. By the time of diagnosis, most people know something is wrong, and many know what is wrong long before they say the words. People in the early stages of dementia speak of “coming out,” with

all the fear that phrase entails. Others lie, knowing how the diagnosis will change the behavior of those around them. Dementia can be a black hole into which all of a person’s power disappears: he becomes an object to be talked about by others, spared—or deprived of—life’s countless choices.

Yet people with Alzheimer’s consistently rate their quality of life higher than their family members do. In a large international study, people with cognitive impairments were no less

happy than healthy people. When family members are upset about a relative’s decline, certain it is a terrible experience, they are not always clear about who is suffering. My friend Kate’s mother had Alzheimer’s. She had always worn careful makeup, and she was uncomfortable leaving the house without it. But her makeup became exaggerated, almost clownish, and she refused Kate’s help. Looking in the mirror, she liked what she saw. Going out to a restaurant became, for Kate, “an exercise in my own dis-

comfort, being willing to let her be as she was.”

I am testing Dorothy, who has moderate dementia. She is still able to walk and to help with what are called the activities of daily life, such as dressing and bathing. I give her a SLUMS (St. Louis University Mental Status) examination, a common tool for gauging the degree of impairment. She does not know the day of the week or the year, but she can do three-column subtraction correctly. She cannot remember a list of five objects or even that I asked her to remember a list. When I have her draw a clockface with a particular time, she neatly puts the numerals in reverse order and flips the hands. She cannot distinguish a triangle from a square or a circle. She remembers no details from a brief story I

tell. When I ask her to name as many animals as she can in one minute, she quickly begins, only to stop repeatedly and discuss them: “Giraffe—they just run around, don’t they? Chicken—I guess chickens are animals. Pigs! We had a farm and I liked the pigs!” Dorothy’s final score is 5 points out of 30. (My score, and likely yours, would be 30.)

After the test, I asked Dorothy how she was feeling, and she said, laughing, “I feel very good all the time, oh boy!” I can see the reader shaking her head and saying, “But that’s the disease talking.” Perhaps. Perhaps the changes in mood that occur with dementia are a result of the physical changes in the brain. In time, many emotions are blunted. A family member worries about how to tell her relative the news of her diagnosis only to find that the patient accepts it with little emotion. The disease dulls knowledge of the disease. Sometimes people with dementia develop depression and anxiety; others forget to be depressed and anxious, forget to be sad. Another friend dreaded the task of cleaning out her father’s enormous storage unit, used as she was to his intense attachment to his possessions, remembering his anger at having to give up his apartment. But when the time came, his emotional connection to everything he owned had faded. A book had become just a book, a cup just a cup, and no longer the repository of past regrets and plans. He likes his new room just fine.

Mind is only part of what we are; we are also shapes inhabiting space. A good deal of my life is spent below conscious thought. I wash the dishes more or less the same way every time while thinking of many other things or nothing in particular. This is what we might call the felt self, the familiar patterns of the body, the home inside

the skin—a literal skeleton in which habits and memories reside. Even after a person can’t speak, she can understand body language, tone of voice, facial expression. When the words a person speaks are nonsense, they may still retain the rhythm of speech, and you can sometimes figure out their meaning just by listening to the cadence and the tone. Even when a person cannot speak at all, he will still shake hands. We can’t really parse this rich matrix, except to note



that losing one’s mind is not exactly losing one’s self. Glen Campbell still was able to perform after he was unable to get dressed alone. Which of those acts was more his?

Reality reorientation therapy was all the rage for many years, though it was exquisitely frustrating for everyone concerned: the continual correction of a person’s misperceptions and forgetfulness, as though the shrunken, tangled brain could relearn the details of the here and now. As this type of therapy lost favor, caregivers began to adopt the Best Friends™ Approach, in which one is supposed to use “the language of friendship” rather than a professional tone, as though one has known the person for a long time. This works with Betty; I jolly her along. She has Lewy body dementia, which causes hallucinations and Parkinson’s-like motor

problems, and she responds to this approach. I am always bright and friendly with Betty. “How are you?” I say, leaning in. “I just dropped in to visit.” But I would get nowhere doing this with Mr. Franklin; he is offended by the offhand manner of the staff, as I am sure he has been offended by familiarity most of his adult life.

My mother-in-law, Phyllis, was a masterful knitter. She gave each of us a perfect sweater every Christmas.

But one year, only a single sweater arrived: a Frankenstein’s mess of different yarns, one long and one short sleeve, speckled with dropped stitches. She kept knitting for a while, and then she just liked to touch the yarn. The policeman walks his beat up the hall, down the hall, back again. The singer sings. John prays: “He ascended into Heaven and is seated at the righthand of the Father he will come again to judge the living and the dead believe in the Holy Spirit the holy Catholic Church the

communion of saints the forgiveness of sins the resurrection of the body and the life everlasting Amen.”

Sometimes people with dementia seem to become their own opposite. Phyllis was a proper Presbyterian housewife who volunteered at the hospital, but she started lifting up her shirt in public and cursing at us. She hid money in the oven, and in the last months of her life would lie on the floor, arms outstretched, talking loudly. To her family, she seemed to be a different person—not our mother anymore. But I had known her only as an adult; I’d seen her sharp edges in a way her children could not. When the skein of the past unravels, so does repression. The housewife lets the world finally hear the complaints she has been mumbling to herself all along. The stoic man

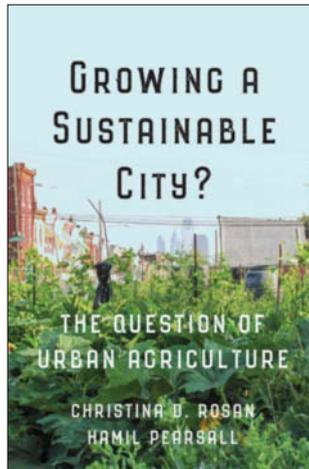
confesses his love. Our deepest needs, the habits of the secret heart, stay with us the longest.

I am never jolly with Patricia, who is serious and formal. She dresses carefully, washes out her stockings every evening, and pins up her hair. Patricia has Alzheimer's. We think of Alzheimer's as memory loss, but it also affects visual-spatial perception, making it difficult to recognize objects, and destroys executive function—the group of skills that allow us to organize and plan, solve problems, and make judgments. In later stages, it impairs language, behavior, and motor control. Patricia does not like to be touched, in spite of her growing dishevelment. She wears the same dress every day now, and her dirty hair is a nest of bobby pins. She carries a doll that is completely alive to her; it provides her with companionship and guidance. I always greet the doll by name and ask after his health. If you want to get anywhere with Patricia, you have to get the doll on your side.

Patricia's refusal to bathe is what we tend to call problem behavior. Hygiene is a good thing all around, but often what we call a problem means a problem for the rest of us. One can be diagnosed with Alzheimer's disease or vascular dementia; one can also be diagnosed with Alzheimer's dementia with behavioral disturbance, vascular dementia with delusions, and so on. An early symptom of Alzheimer's is abulia, which means a decline in initiative, a dulling of motivation and will.

People with dementia get bored, and perhaps the greasy quality of time is part of the disease's progression. Starting a task is hard; staying on a task is harder. I think of that dream, the one in which you have to leave the house by noon to get to the airport, and the clock reads 11:55, so you start cooking noodles and then suddenly remember you have to leave at noon but you get distracted before you reach the door. The emotion I feel in this dream is a frayed fretfulness, a sputtering inability to start. I slide across the crucial point of departure as though on a layer of invisible ice.

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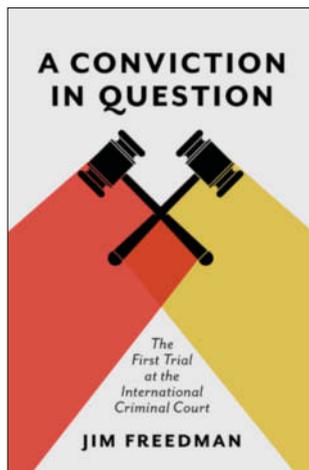


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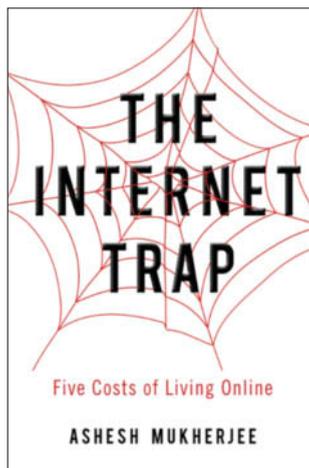


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Advancing Knowledge

People with dementia putter about in much the same way that you and I putter sometimes: sorting dresser drawers, emptying a purse, taking the linens off the bed. That it isn't his dresser and she can't remember how to put the linens back on is not a concern. The patient who was once a nurse tries to bathe her roommate; the onetime chef insists on cooking lunch. People yearn to be active. The worst quality of institutional life is the lack of things to do and the assumption that people don't need things to do. They need to fold laundry, use tools, make art. They need a baby to rock and dishes to wash. These are not patronizing or fake activities. The baby may be a doll, but the caring is very real. It is part of the continuous making of the self, because a self is a thing with purpose.

Mrs. S is in her late eighties. She used to be a store manager, and her arrogant dismissal of the other residents is breathtaking. As her dementia progresses, she has become ever more critical of her caregivers, who to her are clearly incompetent. When she scowls at me, pointing and demanding, "Why is that woman bothering me?" I can imagine the boss she used to be, the way her employees must have scurried when they heard that tone of voice. She is still busy, trying to get the trains to run on time. She harrumphs and rolls away from me. Terminated, with prejudice.

Behavior always has meaning. Betty walks almost constantly in the hallways of the locked unit, walks to the door and presses her whole body flat against it for a moment, unmoving, then wanders on. Sometimes she picks up an item and carries it all day—a hairbrush, a houseplant. Now she goes into Frank's room and begins to methodically take down the curtains. Thwarted in her momentum, Betty can get angry, so dealing with her requires a little delicacy.

"Betty, hey!" I call out. She looks at me vaguely and turns back to the curtains. "Can I help you with that? Let's go get a ladder." She looks uncertain but finally drops the curtains and turns toward me. I take her hand. We stroll down the hall, the curtains already forgotten.

Have I lied to her? It doesn't feel that way. The medical and nursing communities use stigmatizing language: "wandering," "elopement," "feeder," "aggression." I am trying to meet her rather than overcome her. People with dementia have been tied down and given massive doses of major sedatives and tranquilizers, even electroconvulsive therapy, to control problem behaviors such as taking down curtains. We behave as we do to meet needs. I eat because I am hungry. I put on a sweater when I am cold. I will hit a stranger who tries to take my clothes off. (What we call aggression is often self-defense. A trainer for caregivers says that if a person is aggressive, "you're the one who started it.")

A person who wanders, such as Betty, can be trying to get somewhere in particular; when she is a little amped up, as she gets sometimes—pushing on the locked door, banging on a window—she may be trying to go to work or pick up her kids after school. If Mr. Franklin refuses to eat in the dining room, he could be banished to a special table for people who need help with meals. But Mr. Franklin may have eaten alone all his adult life. Maybe Mr. Franklin thinks he is in a restaurant (many assisted living facilities go to some trouble to create this impression) and is afraid that he won't be able to pay the bill. Figuring out why a person behaves as he does is not just part of my job. It's what I do every day with each person I meet. It's what I do with myself. Why did I say that, why did I do that when I know better? I don't always know.

Time changes when the brain fails, becoming strange and plastic. This is time unmoored; a person drifts like an astronaut on galactic winds, encircling the perishable moment. One lets go of any insistence on the linear and apparent. The rate of speech slows down, eventually becoming so slow that it sounds like nonsense. (Recorded and sped up, though, the words may make sense.) At the same time, words take on new meanings and syntax changes. People often repeat themselves, reach for words, or use images. One woman would say "my butt is drunk" when-

ever her pants were soiled. All verbal sense eventually disappears, decaying into the jumble called word salad or into the frustrating silence of aphasia. Dementia gives us an opportunity to question how time and language and perception work. It strikes me that both artistic and religious practice have these qualities: new ways to use words, repetition, pauses and silences, gestures and images—expressions of the expansive interior longing to be heard.

As dementia progresses, a person loses the ability to "update" her knowledge of herself. The self begins to stutter to a stop, to freeze. A person never stops changing, but a person with dementia is eventually unable to learn that he or she is changing. Our most vivid sense of ourselves is from adolescence to about thirty; this is called the reminiscence bump, and many people seem to freeze there. Only the most robust parts of the story remain. She is not your mother anymore, but forever a version of the mother you had. The story is told again and then again until it becomes a kind of fable: a story told only one way.

The script is gone, patterns break, the long-danced dance is different now. When words fail, you rely on sight and touch. All the big and tiny slights of life are done. If you are comfortable with silence, you know that silence is a fertile thing. You let go of words, the exchange and chatter and demands, and rest. You pay close attention. Everything has changed; there is nothing to fear.

In the final stages of dementia, the diminished brain no longer interacts with the world. Is coherent memory gone, or has the person simply folded in on it? We can't know for sure, but the body forgets even its oldest habits. From a very young age, a person knows how to eat, to open the mouth, to chew, to swallow. A person with dementia will continue to eat for a long time, as he always has. Then perhaps he wants to eat at odd times, or wants to eat the plastic flowers. Then he stops lifting the spoon but opens his mouth if you lift the spoon and chews. Then he stops chewing and, finally, stops opening his mouth. Eating is no longer interesting, or it's

too complicated; even the act of swallowing is forgotten. In the same way, a person will walk all day long, never stopping for more than a few moments. Then she will walk part of the day, and then not much, and then not at all. Walking is too complicated; it has been forgotten. Dementia is invariably fatal, which is a puzzle to many family members. How can the loss of memory kill you? One forgets to do what keeps one alive. The immediate cause of death is usually related to malnutrition, the consequent failing immune system, and illnesses of immobility, such as pneumonia.

Paul Broks describes living brains as “progenitors of infinite space,” universes unto themselves, and the dead brain as “a point at which the universe has collapsed.” But I sometimes think of dementia as the long way home. Most of us will die by degrees, and everything lost in dementia is in time lost to all of us. What I feel the most in the world of the demented is wholeness, the unknowable and almost overwhelming wholeness of a single human being. I touch this now and then as I do my errands, hurry off to work: every person I see is beyond measure. The tired woman on the bus, the intent young man riding his bicycle the wrong way up the road, the smiling neighbor nodding at me as her snuffling boxer pulls her down the steps. I walk down the hallways and watch people gently orbit one another: singularities. Patricia, her hair a careful riot of bobby pins. Albert, banging his walker. They are planetary, enormous.

Betty is cheerful today. She agrees to sit beside me on a bench for a few minutes. She takes my hand, leans her head on my shoulder. She eats little now and is very thin; I can feel her hip bone against my thigh. All at once she smiles and looks at me. “I have *everything* done!” she announces, great satisfaction on her face. “Everything done. It’s all going in the place that goes in the place for each.” Everything done, at last.

What a wonder it all is, that we appear and abide and fade away and no one knows what follows. ■

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Edmund Clark, Redacted image of a complex of buildings where a pilot identified as having flown rendition flights lives, from *Negative Publicity: Artefacts of Extraordinary Rendition*, by Crofton Black and Edmund Clark

Edmund Clark:
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