

NON-FICTION | SPRING 2020

And Not To Be

By Adam Lalley

Medical training has taught me to hear the mumble of symptoms with which death begins to articulate itself, and this is the sound it made with my grandmother. One day, she nodded off in her chair, and when she eventually was roused, her speech was slurred, her vision was blurry, and she wasn't acting like herself. By the time she arrived at the hospital, her symptoms had resolved, but a scan showed nine masses at the gray and white junctures of her brain. My mother told me the news over the phone, but I was the first in the family to understand it. I told her to consult Palliative Care.

For years, my grandmother had been falling. But despite lacerations, a fractured patella, and an abiding pain in the hollow behind her knee, nothing stuck to her. In the thick of her seventies and eighties, she had shrugged off a quadruple bypass, appendicitis, even a septic spider bite. She had reserves of life that were nothing less than astonishing. For my family, to watch her continue into her nineties was actually suspenseful.

After nodding off, she survived for five more months, and in that time, she became easily disoriented and incontinent. She forgot my mother's name and seemed not to recognize me. She could not be convinced that her son, when standing before her, was the same man to whom she spoke so often on the phone. And at the end of a visit with her, after I had fed her, she reached out to shake my hand and said she hadn't caught my name; she wanted to thank me for everything I had done for her that day.

Her ignorance was not bliss, but it was a reprieve; she had lost enough of her sharpness to become oblivious of what was killing her – a state of mind known as anosognosia – and her weakening memory allowed her to forget that she was dying. Eventually, her gray eyes fogged over, and she stopped speaking. We thought she was going blind, but there was no way to tell.

In *The Emperor of All Maladies: A Biography of Cancer*, Siddhartha Mukherjee writes that cancer is us, that its cells (that is, our cells) "live at the cost of our living. Cancer cells can grow faster, adapt better. They are more perfect versions of ourselves." If there is a poetry to cancer, its theme is betrayal. It reads like this: cancers arise not from without but from within, not from microbes but from mutations. A more sinister part of us learns the trick of immortality, and in a war of attrition, we have to kill our own cells to kill the cancer. If we fail, our final revenge is our own death, which leaves cancer without a host.

In medical school, professors taught me about the immune system by similarly invoking the language of "self" and "not self" when referring to what the body accepts versus what it rejects. And yet at the same time, I learned how frequently this distinction breaks down, particularly in autoimmune conditions. What does it mean to have a "self" on a cellular level? I don't take credit for what my nephrons accomplish, nor am I proud of my microbiome, even

when it achieves something I desire. The body is a field on which competing interests collide anabolism and catabolism, growth and conservation, integrity and symbiosis. If I am my cells, death is only a part of me: I am the cells that have been sacrificed as much as I am those that have survived. Unless I am neither.

At what point exactly did my grandmother die? In Plutarch's account of Theseus, who slayed the minotaur, he wrote that the mythical king's ship was preserved in Athens for centuries, and as each plank decayed, it was replaced by new timber, piece by piece. Philosophers began to wonder at what point the ship, through its gradual restoration, ceased to be the original, and the question itself has been preserved until our time. Now, in an era of prosthetics, organ donation, and blood transfusions, the question becomes more and more salient of our bodies. Genetically, materially, experientially, we leave pieces of ourselves in others and are in turn made of others. Without a clear epicenter for the self, what does it mean to "pass away," to go further and further and yet not be gone?

Ten years ago, my grandmother had told me her time was coming. She'd said the same thing to me five years ago and two years ago. She said all this because she wanted me to know that she was ready. Three days before she was declared dead, she was declared dying, and my wife and I took the train east to her assisted living home. Her room was deeper in the building, in a wing reserved for patients with dementia. The exits were disguised as walls, like secret passageways, and a three-digit code was needed to open them – too many numbers for anyone residing there to remember, though a year ago my grandmother was balancing her checkbook.

In her bed, she was propped up on pillows, and all four limbs were wrapped in bandages. She had stopped speaking three weeks earlier, and it was unclear whether she had forgotten the words, lost all ideas, or lost the will. Now, her skin was as thin as the membrane between an egg and its shell, and the slightest pressure could tear it. The barrier between her and the world was breaking down; she was evaporating.

The steam that leaves the body through burns, open wounds, abrasions, or the skin itself is known as "insensible losses," a departure that is difficult to measure. In my grandmother, I was witnessing another kind of subtle, incremental loss and the impossibility of quantifying it.

My wife and I sat beside her for two hours, with long stretches of silence punctuated only by her breathing. There was an odd pattern to it. Eight to ten deep, slow breaths would usher in a long pause, a break in the rhythm, a short death. Then her body would spark and begin the cycle again. The first time my wife noticed this, she nearly leapt out of her chair. The breathing split me in two: worried and saddened, I also felt the flush of knowing what it was. From a textbook I had read years ago, I recognized it as Cheyne-Stokes breathing, though I had never seen it in person.

The detachment, academic as it was, gave me a place to put my grieving. In my head, in a way that's difficult for me even now to completely understand, she was already gone. Perhaps I was inoculating myself against the inevitable. Or maybe I was fashioning an artificial threshold through which I did not want to add new impressions of her, so as not to contaminate my old

memories of her. Past the threshold, her behavior and appearance could be more easily forgiven – I could tell myself it wasn't really her; it was the dying version of her. But that threshold was porous, and there was no easy way to compartmentalize her in time. To alter Hamlet – a man who was haunted by a ghost – perhaps being and not being can be simultaneous.

Twenty-nine years earlier, when my grandmother's husband died of kidney cancer, I had been gifted a small box of his belongings: a photo of him as a younger man, a pin, some unpaired cufflinks, a gold tie clip. I was a young boy of eight. The box smelled like him, and when I missed him, I opened it to look at his photo then closed it quickly again to preserve the scent. Not entirely believing in heaven but still thinking he could somehow see me, for years I tried to behave in a way that would make him proud.

Now, to me, my grandmother's body was itself like a memento of her, an old adornment she had already left or would soon leave behind. The time it was taking her to slowly pass away seemed commensurate with the complexity of packing up a soul to move it elsewhere, and I was thankful to her body for allowing an opportunity to say goodbye.

In the hours we spent beside her, not expecting anything at all important to happen, I told myself that she knew my wife and I were there and that it would be okay with her if we didn't try to wake her. Before leaving, I kissed her on the forehead lightly, so as not to tear her skin. I said I loved her, that I always had. I hesitated to say I always will, not knowing exactly what that would mean. I had no idea if she could feel what I said, but whether it was the part of her in her or the part of her in me, on some level, the words felt received. She was gone, and she wasn't, is gone, and isn't.

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