

DERELICTION OF DUTY

Anne-Christine Strugnell

I have a neurological disease: progressive supranuclear palsy (PSP). “Progressive” is a bad thing in disease-talk, even worse than “untreatable,” which is one of the few understandable words they use to describe this illness.

After all the doctors finished softening their messages for me, pushing them through euphemistic medical terms like I used to smush overcooked vegetables through a strainer for my babies, I realized it came down to this: I would inevitably—and soon—become a paralyzed and speechless feed-me change-me doll.

“So, Mrs. Linden, I understand you’re asking for support in refusing food and water, what we call “dry death.” Help me understand: why do you want to end your life?” the young hospice worker asked me, her earnest eyes on mine.

They say I have issues swallowing food and water now, but it was the absurdity of the question that provoked the snorting sound I made. Wasn't my prognosis a sufficient reason for a woman to want to end her life? It would seem not. I would have to make up another reason.

"I don't want my family to have the burden of caring for me," I said. I thought that sounded good. Maybe even heroic.

Two of those family members were in the room: My second husband Matt and my daughter Clara. Clara was running the show, as always, and she immediately brushed it off. "We don't mind," she said, earnestly, reaching out to give my hand a little squeeze. I didn't squeeze back.

I tried again. "I can't really afford years of nursing care," I said. "That would use up my savings and leave nothing for my children."

"But Mom, we'd all rather you live a comfortable life for as long as you can. We don't care if that leaves no inheritance." Clara meant it, too. I could feel irritation rising in me like the itch of a wool sweater on bare skin, but I couldn't tell whether I was more annoyed at her or at myself. She'd learned to play the selfless role from a master.

“You would all be better off without me,” I said, trying to sound gentle and wise, but as soon as I heard the words I wished them back. It sounded like I was begging for reassurance, like a dog whining for an affectionate pat.

“That’s just depression talking,” Clara said triumphantly. Now she sounded just like those damn doctors: The moment they can pin a clinical label on my suffering is the moment they stop listening. For them, I become a solved puzzle, not a person in pain.

Cornered, I blurted out the truth. “I don’t *want* to live,” I admitted, and immediately felt ashamed.

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At least my mother wasn’t alive to hear me, but I knew exactly how she would have reacted. Her eyebrows would have shot up so high in disapproval that they would have smoothed out the deep furrows between her eyes. She would have shaken her head and with an indignant huff of breath would have opened an attack on the self-absorption of *I don’t want*, closing it with a stern reminder of my duty to others.

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Duty. PSP has taken so much from me: my ability to engage in a fast-moving conversation, to play with my grandchildren without scaring them

with my confusion, to keep my balance and move free and strong. But it hasn't touched my sense of duty, still a vigilant chaperone in my shriveled body, keeping me alive when I want to die.

For 77 years, my sense of duty to others and the desire to pursue my own happiness have struggled with each other, and though duty has won almost every battle, desire has never surrendered. There have even been times when I thought it had won: such as when I first left my parents in France and took a boat across the Atlantic. I danced with abandon at the too-loud late-night parties on deck, I smoked, and I fell in love with a man who was not Catholic. I even married him, under my parents' stern gaze and in a side chapel instead of at the main altar because he was Episcopalian. And at the wedding, one of my closest friends stood up to toast me—and my wonderful sense of duty.

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I was so busy sparring in my head with my dead mother and guests at a wedding half a century ago that it took a moment for me to realize that in the now, nobody in this room was scolding me for dereliction of duty. The hospice worker was looking at Clara.

Clara resembles my mother, down to the furrow between the eyes, but Clara smoothes hers out with Botox, so she couldn't raise her eyebrows in

astonishment even if she wanted to. She was staring at her hands, folded now on her clipboard of questions. Her nose had turned a faint red and her shoulders slumped under her herringbone blazer.

To my amazement, the argument seemed to be over: it appeared that everyone in the room simply accepted the validity of *I don't want*. I've lived in America for more than 50 years now, but the belief that we have a right to pursue happiness still catches me unprepared, still sparks some of the reckless and rebellious glee I felt when I first experienced it.

The conversation turned practical. The hospice specialist explained that if I stopped eating and drinking, I would die within a few weeks, probably even without discomfort. Clara unfolded her hands and began to write down the details: the visits they would make and the medications they would provide to ease pain, diminish anxiety, and quiet the dreadful sounds of the death rattle—my death rattle, I realized with a start. At last, I was free to go.

Sleep on it, they told me. I almost laughed at the advice, and the assumption that my desire to die might be some self-pitying whim, a cry for attention or help. I had already had attention, from specialists all over Boston. But there could be no help, only those doctors' dodges, the occasional *probably* and

maybe and that ultimate denial, the shrug and the escape clause of “*We don’t know everything! Sometimes miracles happen!*”

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They were already forgetting who I was, now that I could say very little. I slurred some words and found them slippery. Sometimes I would think I’d grabbed the right one but when I opened my mouth it had vanished, or an entirely different and wrong one would pop out.

But in here, in the part of my brain that was still mine, I was clear. I had done my own research on the Internet, had learned for myself the grim truths they would protect me from. They tried to draw a filmy curtain of doubt between me and the facts, but I could see I was on a road that led through a living hell to certain death. And from the moment I’d seen that road I’d also seen a shimmering possibility of an exit—an off ramp to nowhere.

“Sleep on it” was, at heart, a request that I give my family some time to get used to the idea. Fine. I would give them one night. They could sleep on it.

In the morning I announced I would start my fast the next day. But my youngest, Monica, who is also my executrix and a CPA, said that she needed me to sign some documents and authorize a few more transfers to minimize taxation of my estate and make it easier for her to wrap up my financial affairs.

I saw right through that. She was trying to buy time so I would change my mind, and she knew me well enough to choose the only strategy that would work. Duty would not let me leave my affairs in disarray for her to sort out.

I waited a long month, though every day was like a barbed bead on a rosary, cutting as it passed through my fingers. I have known years of days like that. At least this time, I knew the days were numbered.

Everybody had their projects for me in those weeks, ostensibly for my benefit. My husband Matt kept encouraging me to work on puzzles, telling himself and everyone who would listen that by exercising my brain I could fend off the advance of the disease. He took me to visit museums and parks, as though I would discover a burning passion for Renaissance artists and vow to stay until I earned an art history degree. Monica came over every few days, often with new papers and checks for me to sign, though she always made it clear she wasn't ready to release me yet. She also brought her children to visit and talked up the joys of Christmas with young children, but it was July and I wasn't born yesterday.

Though Matt never slowed down the happy talk, he hedged his bets and invited our new minister to call. Briefed beforehand, she got right to the point.

“Is there anything that you can recall having said to your children that you think they might have taken the wrong way? That you regret having said?” She leaned forward in her chair, fixing her eyes on mine as though she would force open the locks of my soul.

My illness makes my eyes wander, so I slipped out from under her gaze and glanced at her face instead, studying the nascent lines at the corners of her eyes, the softening of her chin. She must have been in her mid-forties, which almost excused the unanswerable naïveté of the question.

For a moment I could hear the blood rush in my ears, flooded by the memory of what it had been like, all those years raising five children on my own, worrying what I was inflicting on them with my divorce and dating, and anxious about paying the bills. I remembered the struggle to start a career on nothing but a decade-old BA in sociology, while juggling my schedule and babysitters so that someone would be home by the time the kids came back from school. What was she thinking?

Of course I did some damage, dear minister, I wanted to say. But you're still too young for your calling if you believe we could go through the books of my life line by line and straighten everything out. Why don't you instead ask how many hundreds of times I refused to listen to the voice of "I want,"

about the mornings when I would splash my tear-swollen face with cold water and put on a serene smile before waking the children? and speaking of serenity, doesn't having attended all those damn Al-Anon meetings add up to something? Can't I trade them in for a carte blanche and be excused everything without having to confess it all first?

All those words trying to come out at once jammed together in a tangle as solid as a multi-car accident during rush hour. As I struggled to reply, I caught a glimpse of myself, reflected in a windowpane backed by a dark evergreen. Sitting there with my mouth slightly open, I looked like a little old lady who's halfway gone.

That's when it struck me that nobody should be expecting me to be responsible any longer. And that maybe they didn't. Maybe they were ready to relieve me of duty. Maybe they were just waiting for me to sign off.

So I tried it out. Without a word or gesture to acknowledge that I had heard the minister, I toed my wheelchair over to some flowers in a vase and started removing the spent blossoms, one by one, with a deliberate slowness, as though nothing else required my attention, as though a question did not hang unanswered in the still air of the kitchen.

Out of the corner of my eye I saw the glance she exchanged with Matt, a quick shrug. I remembered the look of glee my children would get if they managed to pocket a cookie when my back was turned. The thrill of getting away with something would make them reckless and exuberant and give them away. I had to be careful not to show the hot edge of my triumph. I kept my back turned and debated whether it was safe to start a monotonous hum or whether that would be hamming it up.

The minister left shortly thereafter, probably to get started on my eulogy, and fast on her heels came another visitor.

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I've known John for decades, ever since he came as a gangly 20-year old to rent a room from me and ended up becoming one of the family. I love him like one of my own children, but today I wasn't in the mood for him. Still bound by habit, I made conversation like always, short, easy questions about his work, his wife, his kids. But he'd heard of my plans from the others and during a pause in the conversation his face suddenly took on a sober look, like he was going to talk about the history of our relationship and the meaning of it all.

I suddenly realized I was done with talking. I didn't want to explain anything, didn't want to listen to another word.

Remembering the lesson of this morning, I decided to take the role of half-way gone little old lady out for another test drive. I pressed the buzzer on my wheelchair, and when Matt appeared, I said, "John is done visiting now."

John looked startled. But who can argue with a confused little old lady with a death wish? I was discovering the thrilling truth: nobody could.

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Larry came next, my reformed black sheep. I knew it was him just from the way he opened the door, aggressively, like the door was thinking of resisting him. He clumped in wearing his motorcyclist's boots and his hand grazed the top of my hair in greeting as he flopped into the low chair facing me, his knees spread wide.

"How you doing, Ma?" he asked, his tone, as always, bordering on the belligerent, suggesting we could turn the conversation into an argument at any moment.

"OK," I said. "Monica says soon."

"Yeah, she's gonna give you the green light soon, she says, maybe in a coupla days," he said, his voice as always sized for his auto body shop, not my

little sunroom. “But hey, Ma, you know, I’m not gonna be here. I’m headed to Sturgis for the Harley rally, same as always. I’ll be gone maybe three weeks.”

There was a pause in which we both weighed the odds and decided that it was extremely unlikely we would see each other again. Neither of us said it.

“Going anywhere afterward?” I asked, not yet free of the feeling that I had to make conversation.

“Yeah, it only takes about a week to Sturgis, a week back in a straight line, but I’d like to drop down further south and hit Graceland on my way back,” he said, and started telling me about the jazz scene in Memphis.

I realized that I was done with him too, my second son, my mischievous heart-breaking formerly blond boy. I was done loving and hoping and worrying.

I rang my buzzer again, and Matt appeared.

“Larry is done visiting,” I announced.

I didn’t look at him, but I felt a skip in his breath, a pause as he registered a change in my constant dependability.

Startled, he laughed, hard, and rose to his feet, then bent and gave me a two-armed hug that almost lifted me out of my chair.

“Bye, Ma,” he said, and he was gone.

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Matt hovered.

“Are you OK, sweetie?” he asked, using his concerned therapist’s voice on me. But I was done being therapized, too. Yet another thing I didn’t have to play along with any more. I silently wheeled my chair across the room to sit in front of a puzzle, knowing that Matt would be happy to think that I was working on my mental acuity. With my back to him, I rattled a few pieces to make him think I was working on the puzzle, while I silently vowed never again to lock a puzzle piece in place.

He bumbled around the kitchen, making himself tea before wandering out, leaving me untroubled and alone. The minister’s question about regret rose to mind once more, but I shrugged it off. I was done with regret.

This dereliction of duty was delicious. I had not known it could feel like this, hadn’t even realized before that it had always been a possibility. All along it could have been as easy as letting a question hang unanswered, letting an accusation float free in the air, or closing a visit when I felt like it rather than waiting for the other person to release me from further obligation. Words only had power over me if I wrestled with them. If I just let them float, they were nothing.

I wished I had known decades earlier that it could be so easy. Still, though my victory over duty had been late in coming, it would last long enough to see me out.

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