

The Caregiver

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Lee wraps her shawl close around her shoulders and looks out the window. If she'd been given a choice, she'd have chosen one cataclysmic storm, with thunder, lightning, branches breaking, windows rattling, power failing. She would not have chosen this persistent grey drizzle, this leaden cloud cover. But she hasn't been given any such choice. Esmelda won't be in, of course. David is also gone, and his bed will go today. Lee stripped it late last night when she got home. Vital Mobility has already called to confirm the pickup. Lee wraps her shawl closer and nods, mustering resolve. It's too quiet. The background noises, Esmelda's Spanish radio programs, the rhythm of the ventilator, the beeping of the monitors, all the usual sounds of their living are gone. Will she ever get used to the silence?

Why hadn't it made her cry, stripping the bed, pulling off the sheets, the absorbent pad, the egg crate topper? Instead of crying, she'd run her hands over the mattress, its smooth polyurethane cover, cool, unlined, like new. She hadn't really expected David's body to change it, and yet, she'd felt *something*—a pang of grief or dismay, something like that—because the mattress was exactly as it had been on the day it arrived. And what to do with the sheets? They wouldn't fit any of the beds in the house. Could she donate them? Could a caregiver in her support group use them? She'd have to remember to ask.

Once the bed goes, she'll bring the furniture out of storage, turn this room back into a living room. Her boys can help. In three days, Tim flies in from London, Ray from Vancouver. Wives and children, too. Where will they all sleep? Could her grandkids camp in here? By the time they arrive, David's things—back-up generator, monitors, suction machine, bed boards, and lifting holsters—will be gone. Yes, this room will do, but she'll have to lug the air mattresses and sleeping bags up from the basement. Ray and Helen can use Ray's old room; Tim and Julie can sleep in Tim's old bed, which is now in the dining room. Lee won't sleep in the master bedroom. Nobody will. Nobody has since David moved into the hospital bed in the living room and Lee had Tim's bed moved into the dining room. Instead, Lee will sleep on the couch in her office. She nods, at least she's managed this bit of planning well.

Lee turns from the window and walks to the back of the house, to her office. Only four patients today. She clicks on the electric fireplace, checks that the afghans and pillows are in easy reach, the tissues stocked, the water bottle full, the glasses clean. In the foyer waiting area, the coat rack, boot mat, umbrella stand, and coffee machine are tidy and ready. Lee has time for coffee and the phone call before her first patient arrives.

“Good morning. This is Dr. Stone.”

“Hi, Dr. Stone! This is Katie. Good timing. I’ve just come from Dr. Stone’s room.”

“Good. I’m calling for an update on his night.”

“Of course!” The clicking of a keyboard. “Umm... right... here’s the note. Dr. Stone’s first night went well. He seemed agitated after you left. You know, eyes rolling, blinking, crying. But he settled after a bit. He tolerated his feeding well. No obvious signs of discomfort or pain. He slept soundly.”

Lee’s shoulders fall. “And this morning?”

“All good. We just finished his hygiene and feeding.”

Lee nods. “What’s on his schedule today?”

“Umm...” More keyboard clicks. “Routine intake assessments... nursing, RT, functional...”

“Sounds busy. Is it too much?”

“Don’t worry. We’ll pace it. Give him plenty of rest time.”

“Good. I appreciate it. I’ll be by this evening.”

“He’ll be glad to hear that.”

“No, please don’t tell him. Just in case.”

“Oh, sure. Whatever you like.”

Lee clicks off the phone, silences the ringer, waits for her first patient to arrive. She was right to resign from the hospital, to start a private practice. She and David had plenty of space. A few simple renovations, added on to the larger project of preparing the house for David’s wheelchair, had created her waiting area and office. In private practice, she controls her days, can stay close to David, help Esmelda. Also, today’s patients have forced her out of bed, into the shower, into clean, presentable clothes. She’ll be no good to David if she, too, is immobilized.

#

A tentative knock. A new patient, DM. Chronic pain management. At the end of the hour, DM leaves, her eyes red and puffy. Lee writes her assessment note and begins drafting a plan for DM's transition back to full-time teaching.

"Dad is transitioning into hospice."

"That's good, Mom," said Ray, "it's been so hard on you." Reasonable. Understanding. Accepting. But that was Ray.

Tim was harder. Always had been, even as a baby. "Why now?"

"He's gotten worse. It's progressive. Esmelda, I, we can't handle..."

"So hire more help. You can afford it. I can help some. Ray too, probably."

"It isn't the money."

"What then?"

"Tim."

"He doesn't want hospice."

"I know, but..."

"But what? Dad wants to die at home. And he's *not* dying. Not yet."

Some variant of this conversation several times since. Not even Ray could sway him, convince him that neither of them, so far away, can really know. Tim will be convinced only once he sees his father, watches the nurse suction his lungs. Then he'll hold his mother, press her to himself in silent apology.

That hug will heal something in Lee, but it won't ease her shame or guilt.

"Should we come?" Ray asked.

"Soon, maybe a few days after he's admitted, once he's settled."

"Mom, how do I say goodbye?"

#

Lee's next patient rings the buzzer. She'd started seeing SP with his wife for marital therapy, but now is treating him alone for depression and anger over the dissolution of his marriage.

After David's diagnosis, after the numbness of the shock wore off, after the flood of fear and anger ebbed, before he lost use of more of his body (already his left hand was weak, unreliable), David and Lee met with colleagues—neurologists, occupational therapists, respirologists, home-care nurses—to learn about treatments (palliative, only), prognosis (terminal, always). These meetings forced them to speak it aloud, to confront the realities, to make choices. "Those weeks," Lee will tell her therapist, once David's death is no longer sensitive to the touch, "when David and I came together like that, were the most intimate, the most meaningful, of our marriage."

But as David's illness progressed, their marriage twice came close to shattering. The first time, Lee shouted, "Exactly! It's your body, your death, do whatever you want. Why should I have any say? Who the hell am I, anyway? Damn you!" She'd packed a bag and stayed in a hotel for two days until guilt and worry pulled her back. They'd reconciled, of course. Maybe they'd even forgiven each other. She learned, after that, to let her once placid husband have his rages, to duck when he flung objects (books, mugs, forks, whatever he had at hand) and words (ugly, hurtful words). Slowly, he grew less and less able to act out his rage.

The second time was when they told the boys. They convened a family meeting, the first since the boys left home. By then, David's left arm was unusable and his right arm was weak, his words were slurred, his fatigue formidable, his fear, *their fear*, unfathomable. But they'd hidden it from the boys during Facetime chats, in emails and texts. *Hide it from the boys* had been their agreement since the boys really were boys. No arguing, no disagreements, no bad news.

"How could you hide this from us?" Tim jumped to his feet, stormed around the living room.

"How long have you known? Why didn't you tell us?" Ray asked over and over, rocking on the couch.

Lee had no answers and by then, she had nothing left, no comfort, no consolation, to give her boys.

And in that room awash in Tim's rage, Ray's grief, and Lee's emptiness, David said, clearly, with almost no slurring, "Your mother insisted we wait. I wanted to tell you right away."

In the dark days that followed, the darkest of their marriage, Lee refused to be broken by David's betrayal, and promised herself, instead, that she would be a good enough wife. After all, she couldn't divorce a dying man. She was not a monster. And so, she swallowed her resentment and her rage, and they have deepened and festered.

Her friends, her therapist, even the members of her caregiving group urge her to be positive. They expect her, perhaps on account of her profession, to have some special dispensation, some special reserve of strength, wisdom, acceptance, some special armour against rage and despair. And so, she says less and less, while she shapes herself more and more into the caregiver they need her to be. She waits for her time to rage. She desperately needs to rage.

Lee finishes her note on SP's session, then heads to the kitchen to fix lunch. Will David's next feeding and suctioning be all right? She's had trouble with the finicky equipment, but he isn't Kindred House's first tube-fed patient, not their first mucus-filled lungs.

The fridge is almost empty. Peanut butter and jelly on stale bread, improved slightly by toasting. No milk. Groceries on the way home tonight. Does David need anything else from home? He needs so much now but also so little, or at least, so little she can give him. She checks her voicemail. First Ray and then Tim asking after David. She'll email them later, after her last patient. The Vital Mobility people arrive soon for the bed. Then two more patients.

The men from Vital Mobility are perfectly punctual. The two men, the older one burly, the younger scrawny, remind Lee of an old-fashioned comedy duo. Abbott and Costello. Laurel and Hardy. But no repartee, no slap-stick, no humour. Instead, there is distance, detachment. Paperwork signed, clearances appraised, bed rails rattled, brakes released, and it's done. It takes only a few minutes.

Lee stands where David's bed has been. She cries, quietly. Has she been too rash? Should she have continued a little longer? It's been sixteen months. Not very long; so very long. How do the others do it, keep them at home until the end? Why has she failed?

#

A loud knock. NI is early, as usual. Wiping her eyes, Lee hurries to the back door, welcomes her patient into the waiting area. She will not invite her into the office until the appointed time. Lee goes into the powder room, splashes her face with cold water. Then she sits at her desk, watches the clock.

She has handled it poorly, like a traitor, a double-crosser, slinking off to visit hospices, putting David's name on waiting lists. It is easy now, too easy, to hide things from him, to restrict his reality, to misuse her power. She hoped he'd have one of the sunnier rooms, that he'd be admitted soon. She explained the hospice's at-home assessment as part of hiring an extra personal support worker, since Esmelda couldn't always work overnight.

David had blinked agreement.

If only he could still use the eye-controlled keyboard, but that had stopped weeks ago. Now, he has only the slightest eye movements. Lee tells herself she can still read love, fear, sadness, and anger in them.

After her session with NI, Lee goes to the waiting area, puts a pod in the machine and waits for the coffee to brew. The end of NI's treatment is nearing. Lee stirs whitener into her coffee, returns to her desk to plan the termination. She'll raise the possibility during next week's session, begin preparing her patient.

She avoided preparing David—hadn't even tried—until yesterday morning. David sat propped up in the hospital bed, freshly bathed, shaved, suctioned, diapered, lost in too-large-now pajamas. "David, love, this afternoon." Lee held the military brush. The dark, polished wood, the boar bristles soothed her. David's father had brought the brush from England or France, a memento of war. It had sat on David's dresser since his father died. Before his diagnosis, he rarely used it, but afterwards, he'd use nothing else. Without a handle, the brush's back curved snugly into Lee's palm. She brushed his still damp, mostly still dark, hair. "This afternoon, you... we... we're going... in the transport ambulance." Did he need a trim? Just the back, a quarter inch. "We're going to..." Each stroke an atonement. "To Kindred House." The brush smoothed his cowlicks. "Kindred House Hospice." Hair off his forehead. "It's not too

far." She brushed the hair over his ears. "It'll be easy for everyone to visit." The bristles moved smoothly. "I, we, Esmelda and me, that is, we can't." Brushed it again. "You need expert care now. I worry we'll hurt you." The bristles left furrows in his damp hair. "The bedsore is because we weren't careful enough." Lee looked into David's eyes. Fear, anger. "It's a lovely place, David. They know better. Spacious rooms. Sunny." She gripped the brush, and the bristles pricked her fingers. "I've packed your things. The digital frame, your mother's quilt." Lee put the brush on the bedside table. "I'll pack Dad's brush and your razor, too." She wiped David's tears with her fingers, kissed his forehead. "I'll ride with you in the ambulance." At the foot of the bed, she worked the control panel to recline him. "I'll stay until you're settled." Lee tugged and pushed at the pillows to get them just right, to avoid pressure on the bedsore, and then wiped the tube connecting him to the ventilator. "I'll come see you every day." She wiped his tears again, reattached the oxygen saturation monitor. "I'll read to you. You'd like that, right?" David blinked. "How about a mystery? There's a new Louise Penny."

David looked away, closed his eyes.

#

Lee's last patient, FC, is a recent widow, lonely, isolated, who is struggling to resolve what was left unspoken in her marriage. She has sent a text saying she is running late. Lee fixes another coffee, rummages for a cookie, finds forgotten shortbread in a tin.

David and Lee stopped sharing their bed only a few months ago, when David could no longer help with the transfers in and out of his wheelchair. Despite the wasting, he was still too heavy for Lee to manage alone, especially with the ventilator and feeding tubes.

Their last night together in their bed, Lee held David, cradled him, and spoke into the dark about the beds they'd shared over the years. First, the single in his dorm room, so narrow neither of them could sleep. Then, in their first apartment during residency, the cheap, cheap futon, so hard it knotted their back muscles. Then, the iron bed he salvaged from a garbage-strewn alleyway not long after they married. He dragged it to their musty basement apartment, and Lee brought it back to life with gold spray paint. And, finally, the bed where they lay that

night, where they'd conceived the boys. Victorian, hand-carved walnut with burl panels. Bought at an antique market, after they both secured staff positions at the hospital and bought the house. This bed, too, had needed a little love, a little orange oil, to revive its warmth, its beauty.

After the diagnosis, they still made love, when David felt able, but Lee's desire disappeared when he could no longer move with her, when she could no longer feel his weight on her, when she worried she'd hurt him. She tries not to think of the last time, how he raged, accusing her of being repulsed, of never really enjoying sex, of being unfaithful. Lee thinks instead of those early times in college, when they'd both been new to it all, their conspiracy of discovery and delight, as if they were the first, the only, and of the later times, when they'd loved so well, so richly, before it became routine, ritual.

Once FC has left and Lee has written her session note, she locks the files in the cabinet and leaves her office. She'll forget to email the boys until late tonight, after they've both called again, a tinge of worry in their voices. She'll forget because she is eager to get to Kindred House and worries it'll be very late if there is traffic. Lee gathers the things she's taking with her. She forgot so much yesterday: wash cloths, nail clippers, extra pajamas, warm socks, diapers.

She hates herself for her revulsion, her nausea, whenever she diapers David. Even with Esmelda's help, Lee could not escape the task completely. She and David were unable, unwilling, to look at each other the first time. "Go away," he typed with his eyes. "Leave me alone. Don't touch me."

"He isn't incontinent," Lee explained to the hospice staff, "but the diapers are easier." They'd nodded. Yesterday, at least, they kept him in diapers.

The transport ambulance arrived right on time, 2:00 pm. Esmelda had already said her teary goodbyes, promised to visit the hospice. (When they run into each other at the supermarket, six months after David has died, Esmelda will apologize for not visiting, for disappearing. Lee will hug her and lie about not needing an apology.) Well before the ambulance arrived, Lee had David ready, had packed his things, the ones she remembered. The attendants, friendly but serious, declined Lee's offer of coffee, tea, water.

When they moved towards David's bed, introduced themselves, Lee felt lightheaded, unsteady on her feet. She leaned against the wall, in the far corner, behind the bed, head

bowed, eyes closed and listened to the attendant's explanation, the gathering of the sheets, the count 1-2-3, the grunts as they lifted David, the settling of his body on the gurney, the attendant's reassurances, the buckling of safety belts, the clang and click of raising handrails, more reassurances, and then finally, *oh finally*, the wheels engaging, the gurney, the steps moving out of the room, down the hall, out the door.

Were David's eyes full of fear, betrayal, anger, acceptance?

Lee will never know.

"Ma'am?"

Lee straightened, opened her eyes. The attendant stood before her.

"We're ready, Ma'am. It says here you're riding with us?"

In the ambulance, Lee crouched on the bench, a hand on David's shoulder, cooing to him, to the terror, the rage in his eyes. It had been two months since Lee realized she did not want David to die in their home. She did not want to find him, or worse, watch it happen. She did not want to clean up afterwards. She did not want any of it. Why did he want her to go through that? Why did he want that to be her last memory of him?

"I have broken faith with you. Please forgive me," she rehearsed over and over, silently, swaying with the words, with the movement of the ambulance, but she said nothing.

"David, I've set the frame here. I'll turn it on." The digital picture frame had been Tim's idea. He'd loaded it with hundreds of pictures: David's childhood, Lee and David's wedding, the boys, the grandchildren, vacations, birthdays, Christmases, Thanksgivings. David can watch the pictures, a slide show, with no effort. Lee thinks he likes it. His eyes widened when she first showed it to him, explaining Tim had shipped it from London. They'd watched it together, Lee reminiscing, laughing. David's eyes filling with tears.

On his first evening at the hospice, she stared silently at the screen, at her vibrant, healthy husband, rather than his shell in the bed beside her. That was too far, she chided herself. He was still there, trapped in that broken body that had betrayed them both. Sometimes it was easier to pretend this David was someone else, someone new.

"Your nurse can turn it off later," Lee managed to say. "I'll be back tomorrow."

David blinked agreement.

He did not blink when Lee said, "I love you."

In the taxi home, Lee looked out the window. It was still drizzling. Rivulets ran down the window, creating trails in the glass that reflected the streetlights. One large drop started its descent, stopped, split in two. The two smaller drops made their own paths. One moved slowly, mostly straight; the other curved, jagged, dwindled, and then disappeared midway down.