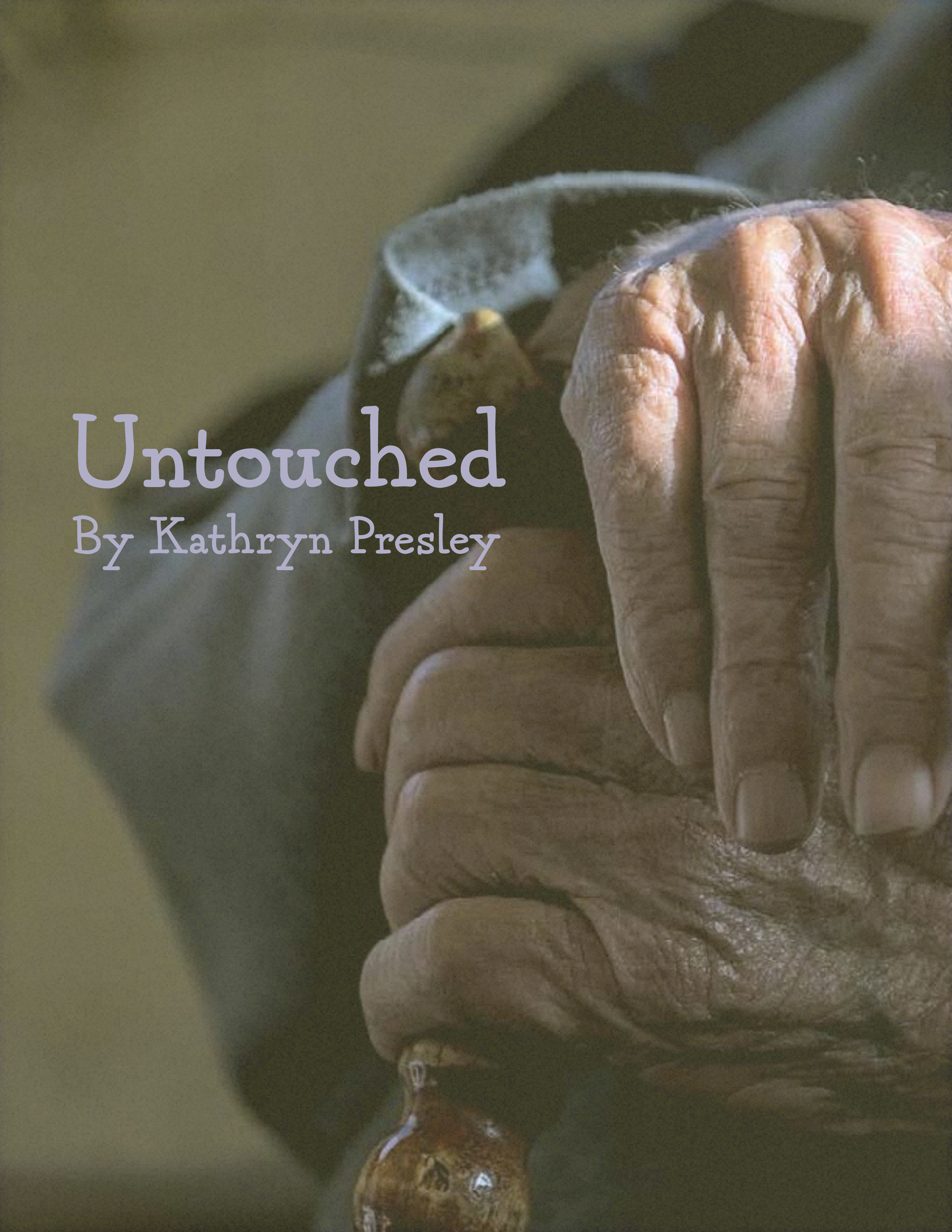


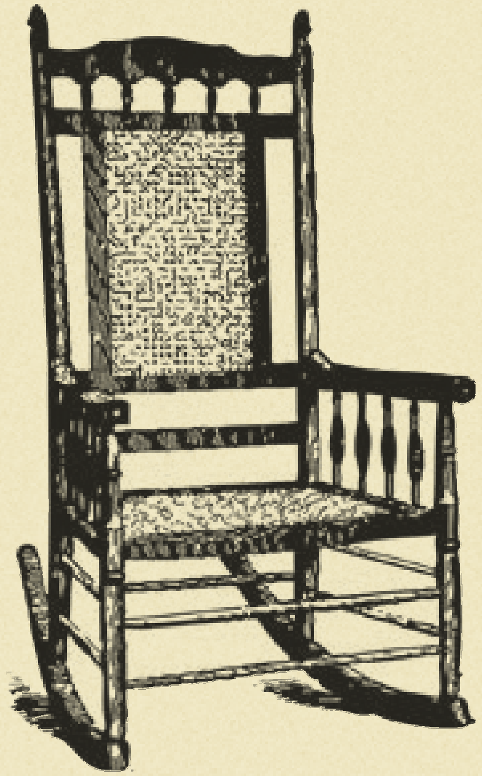
Untouched

By Kathryn Presley

Untouched

By Kathryn Presley

My mother was the primary caretaker for my father before he passed. My brother and I helped where possible, tried to give her breaks, and let her have a life away from my dad. On Mondays and Tuesdays, my brother would drive the hour north to be at my mom's house by eight a.m. and then stay the next two days so she could teach seniors art, run errands, or play Mahjong for the afternoon with her friends. She also belonged to a co-op of artists with a gallery where they took turns working twice a month. I stepped in on those days to watch Dad so she wouldn't have to pay anyone to take her shift. Alzheimer's as many chronic illnesses do, had turned my dad into a time bomb, and we each took our turns watching the clock. It was tedious, tumultuous, and time-consuming even when you weren't "on shift."



Watching Dad consisted of feeding him lunch, cleaning him up if he'd had a bout of incontinence, and keeping him comfortable while answering questions about where Mom had gone, but the main task was in the name itself: watching. Watch him stare blankly at the TV, blaring a game show or movie. Watch him shuffle from the living room to the front porch and room to room, looking for his wife. Watch him run his thumbs over his fingertips endlessly as he grew increasingly anxious as the day wore on. Watch him to make sure he wasn't going to explode into violence in the way we'd heard about other Alzheimer's victims exploding.

> If before Alzheimer's, my dad's face was a facade for a wall, it was now a pane of glass looking into a vast field.

Sometimes, when I went over to watch him, I would perch myself with my laptop at the dining room table, slightly behind him but where he could see me if he turned his head, and I would work on some bit of writing I'd been hammering away at. Sometimes, I'd take Mom's spot in the recliner six feet away from him and settle in for a day of television. That's when I usually took the opportunity to really look at my father. I'd sit and stare, cataloging the differences between the dad I'd known a few years earlier and the one in front of me, ravaged with a disease that was stealing his identity.

The biggest change was always the expression. My father had been quiet, generally, but sharp. He paid attention to what went on around him. He listened, collected, and cataloged conversations he wasn't included in or actions happening around him (sometimes to my mother's and my detriment). In the last two years of his life, that sharp, carefully blank expression turned into something softer and more expressive. If, before Alzheimer's, my dad's face was a facade for a wall, it was now a pane of glass looking into a vast field.

The next thing I'd notice would be his clothes. For a long while, until it was no longer feasible, Mom allowed Dad to dress himself. Unfortunately, this meant that some days, he would go to bed, wake up, and return to bed in the same clothes. Some days, it was worth fighting him about it, but some days, it wasn't. So, I looked over his shirt and pants for spilled food or other incriminating stains. Sometimes, I'd decide to do the laundry, but his bedroom had become a forbidden lair. There were clothes in piles on every flat surface, some folded and some loose, some clean and some dirty. There was the smell of urine and feces that never seemed to go away, even after we'd stripped the room of every piece of fabric we could. There was trash under the bed, dirty diapers in the sink, and an air of disorder. Not every day was this bad, but I came to avoid his bedroom if I could. Walking in was overwhelming. My mom was doing her best, but it was hard to keep up with my dad and keep her sanity at the same time; the guilt of constantly feeling like you were not doing enough for everyone took chunks from your flesh every day.

> Those wide, square, knobby knuckles still looked like they were made of something stronger than granite, even as his mind crumbled.

When I could no longer look at his clothes, I'd look at his hands. Those wide, square, knobby knuckles still looked like they were made of something stronger than granite, even as his mind crumbled. I'd watch him rub his fingers together absently for hours. I began to recognize it as a self-soothing gesture from the research I'd done on what to expect when someone has Alzheimer's. Endlessly, he'd rub his thumb back and forth over the tips of the other four fingers on his hand as if he were feeling the texture of a piece of cloth for how soft or dense it was. I would worry about what made him agitated when I saw him do that. Was there something I could do to help him feel calmer? (The sheer audacity in thinking that I could do anything to ease the mind of a man whose actual mind is slipping away from sand under a wave!)

"Should I try to talk to him? Should I try to touch him? Would he get comfort from that?" I wondered to myself, trying to imagine the scenario where I would willingly touch my father outside of what was absolutely necessary. When was the last time someone touched you for comfort and not out of necessity? I wondered as Dad continued to stare into the middle distance and run his thumbs back and forth, back and forth. At that point, I hadn't hugged him in years or even offered the simple comfort of a hand on his shoulder. And when had Mom last touched him without necessity—not to clean him after an accident or bandage a wound—but ismply for the comfort of human connection?

She would call me occasionally in the middle of the night, talking low on the phone just in case he lurked in the hallway.

"Hon, he came into my room," she'd say quietly, breathless with anxiety. Then she'd follow it with, "He stood by the bed and just stared at me," or "He tried to get into the bed next to me."

"Oh?" I'd answer, interested but somewhat bewildered by his actions also. They hadn't shared a bed since I was a child, and I was well into my late thirties then.

"Yeah. I told him to go to bed. He asked why he couldn't get in bed with me, and I had to tell him we weren't friends like that."

Oh.

Oh.

"Did he leave? Did he say anything?" I asked, making myself anxious by the implications. To my knowledge, my mother has never had sexual violence visited upon her by my dad or any other male, but that wasn't Dad in that giant, lumbering body anymore. That was a stranger we looked after who also happened to be my mother's housemate.

"He said okay, and I had to get up and show him where his bedroom was. I'm pretty sure he's in the hallway, though, so I shut my door."

"Well, okay. I'm sorry that happened to you."

"It's okay. I just . . . had to tell someone about it. I'm sorry. You probably didn't want to know about that."

"Mom . . ." I'd sigh, weary of having to say it for the hundredth time. "It's fine. You can vent about it. You're not tarnishing my memory or disillusioning me about the situation. It's fine. If you need to talk, call. You need to be able to get this stuff out, too."

To my knowledge, my mother has never had sexual violence visited upon her by my dad or any other male, but that wasn't Dad in that giant, lumbering body anymore. That was a stranger we caretook for who happened to be my mother's housemate.

"Thanks. I just . . . had to tell someone. Thanks. Well, I'll talk to you tomorrow."

"Night, Mom. Love you."

"Love you, too."

We'd hang up, and I'd go back to work, watch TV, or do whatever I'd been doing previously. I'd think about Mom and consider her reactions to the situation, wondering if there'd been trauma I wasn't aware of in her past that made her react as she did. Then I'd think about Dad. Always, always, my mind would return to trying to puzzle out my father.

In most of the literature and media that I've consumed about Alzheimer's disease, one of the things that has been said over and over is how, as the disease progresses, your loved one will probably regress to a more childlike demeanor. I wonder if those nighttime visits to my mother's room were just my father, trying to seek physical comfort. (My mother was the one person he recognized without question until he died.)

My father, at full mental capacity, however, was not a physically demonstrative man. He was not affectionate and did not invite affection toward himself; he was emotionally immature and prone to explosive bouts of anger over the tiniest thing. This was something he'd done way before Alzheimer's. My most uncharitable comment on his slow descent into forgetting was that it significantly improved his personality. He was a delightful person when he could easily let go of a thousand silent injuries he'd endured throughout his life. What a breath of fresh air it was for me not to worry that I would offend him unknowingly on Monday and get cursed out two Fridays later, without reference to the original offense.

That was the kicker about his anger and hurt and grudge-holding. We'd never be told about what was done to offend him. For a while, this was happening so often that Mom and I would make a game from it. Not a fun game, but a survival one.

Once he started to kick up a tantrum, she and I would extricate ourselves from his vicinity. We would get in the car and leave. We had no destination in mind except to be where he wasn't. Then, for the first few blocks of driving around aimlessly, we would try to guess what we'd actually done that set him off. We'd lay out our sins against him on the dashboard and try to pick out the catalyst for this week's meltdown. Then, after an hour or two, we would return to the house, where he would act sullen and ignore us until the next outburst.

It's hard to want to hug someone who constantly makes you feel threatened. Even if he never physically hit either of us, he didn't do much emotionally to endear us to physical affection.

It's hard to want to hug someone who constantly makes you feel threatened. Even if he never physically hit either of us, he didn't do much emotionally to endear us to physical affection. Then, when the Alzheimer's had him well and in its grip, it was too late. I tried to remember to pat his hand or shoulder, but it had been trained out of me. He was a predator; he was a villain. He was not to be shown mercy or kindness. I had to protect myself by keeping my distance.

The night of my father's death, he wasn't at the house. He was in a hospice bed thirty minutes away. Mom and I had been hanging out late into the evening, watching movies and trying to ignore the absence in the house. I looked at the clock when we parted ways and thought about how I hadn't visited him in a few days. Hospice is open 24/7. I knew I could visit him. I tried to imagine what that would be like. He hadn't been awake in my presence in a week, but would tonight be the night? I thought about whether he would continue to sleep through my being there. I had "Leavin' on a

Jet Plane" stuck in my head as I drove home, and I imagined singing it to him while he slept. I imagined talking to him about why I was so angry with him. I imagined holding his hand and the feeling of its warm weight covering mine.

I decided not to go.

There are a hundred excuses, but cowardice is the main one. I wasn't ready to confront my own emotions, and I did not want to go there to cry. He passed within an hour of me getting back to my own house.

There is regret in not touching him one last time; there is regret in not viewing the body before it was cremated; there is regret in not finding peace with him before he became a shell of his former self. But there is also relief in no longer wondering if we're doing enough for him. There's relief in no longer waiting for the time bomb to explode. It's been dismantled. It's inert. We can rest.