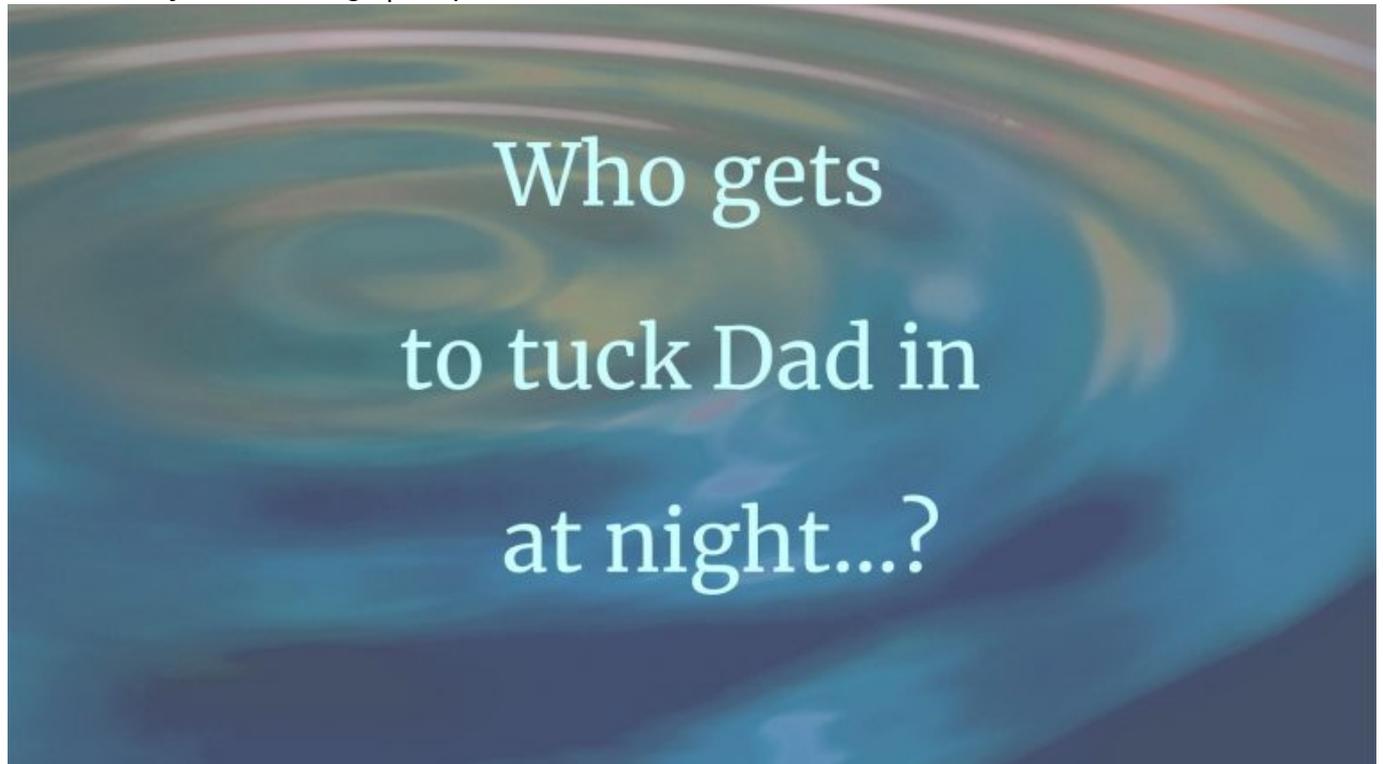


Bedtime Ritual

Category: Stories

written by Mimi Emig | September 25, 2020



I had planned to take care of my dad at the end of his life.

In 2009, Dad retired at seventy-five because of Parkinson's disease. Over the next couple of years, he lived in his own home. My younger brother Mark, who lived nearby, faced the first difficult milestones brought on by Dad's declining health. Mark was the one to tell Dad that he could no longer drive. And after Dad moved out, Mark took on the monumental project of cleaning a half-century of detritus from the house Dad left behind.

Initially, my three siblings and I shared the responsibility of caring for Dad. We sent him packing every three months to upstate New York, Michigan, Texas or Alaska to stay with each of us in turn. Dad had always enjoyed traveling, so he liked rotating among our houses. He called it "vacation," and still referred to New York as "home."

Over the next three years, Dad's Parkinson's disease progressed. He had more trouble walking. His memory started to go. Airplane travel became more and more difficult for him.

We arranged for wheelchair assistance for Dad's flights; this got him safely from one of us to the next. But one spring, as he was being wheeled down the ramp for his stay with me, I noticed that his eyes looked glassy and unfocused.

I thanked the attendants and tipped them, then greeted Dad.

It took him a moment to recognize me. Then I saw that his pants were soaked with urine. A wave of shame rolled over me: I'd had blinders on about how advanced his disease was.

"Dad, let's get you to a bathroom and clean you up," I said.

In a family restroom, I helped him out of his Depends and wet pants. There were clean clothes in his carry-on; I offered Mark silent thanks for his foresight in packing them.

It took a couple of days for Dad's travel "fog" to clear. Meanwhile, I talked to my husband about whether we could handle having my dad live with us full-time. There were lots of reasons in favor of it. As a retired physician, I was good at managing Dad's medical problems; for years, he'd had his routine healthcare visits done in our city. Our house was handicap accessible. Dad already used a walker; if he ended up in a wheelchair, we could still manage. And if my siblings wanted to come and visit, we had enough space for them as well.

My husband was all in. He welcomed my dad there, knowing it was the right thing to do.

I then talked to my siblings, being frank about Dad's progression.

"It's not safe for him to travel between us anymore," I said. They agreed that he should spend his final time at my house.

It was all settled. What none of us could have predicted, though, was how my own health would go downhill over the next twelve months.

A series of complications from a surgery made me seriously ill, and I became frighteningly thin; I had to use a feeding tube to keep my weight up. My medical treatments took ten hours each day.

My husband was working full-time, commuting fifteen miles to work and back every day. And Dad was falling a couple times a week.

If he fell while I was home alone with him, it was hard for me to help him back up. As much as I wanted to be the one to care for him, I knew that I couldn't.

One day, after he'd fallen, I called my younger sister, Christa.

"I can't do it," I said through tears, not stopping to breathe. "I could barely get him up...I'm exhausted...I'm so sorry...I really wanted this to work."

Christa and my other siblings were unanimous; it wasn't safe for Dad to stay with me. There was one final transition for him—to Texas, where Christa took over his care. Mark's adult son flew there with Dad, then stayed a few weeks to help ease him into life there.

Later that fall, I went to Texas for a couple of weeks to help enroll Dad in hospice.

One night I sat quietly on my sister's couch, listening as she shepherded Dad through his bedtime ritual. I longed to creep down the short hallway and peer into the room, to be part of their scene, but I stayed put. I didn't want to intrude on this moment of shared intimacy, to interrupt their bedtime routine.

"Tuck, tuck, tuck," I heard Christa say, as she pulled Dad's covers up around him. "Good night. Sleep tight. Don't let the bedbugs bite."

I marveled at her tenderness in using words from our childhood routine to coax a smile from Dad.

I was far too old for jealousy over bedtime stories. But a wave of sadness washed over me as I reflected that Dad's final months would be lived out at my sister's house, 1,400 miles from my own home.

Silently, I listed my losses: the once brilliant man who was my father, forever altered by dementia; the time that I'd thought we'd have together—time now relinquished to my sister; and my own health, hovering in a precarious balance.

But I also numbered my reasons for gratitude—most of all, that Christa had embraced the principles of hospice in a way that I might not have been able to.

Intellectually, I understood the need to shift away from rigorously treating my dad's health conditions and towards enhancing his quality of life and comfort. In reality, I'd have had trouble letting go of my "doctor" training. I would have monitored Dad's carbohydrate intake to control his diabetes, made sure that he did his physical-therapy routine, and more.

My sister, by contrast, had made a point of bringing levity to Dad's days, trying to make him smile and laugh. Getting him ready for bed at night, she'd try to "score" by throwing his socks into the hamper. She took him to Pancake Joe's every weekend, sneaking in real maple syrup in a flask, because she knew he liked it more than the corn-syrup version they offered. Once a week, she sat in a corner while Dad drank Diet Coke and socialized with his friends at a local club, then listened as he prattled on the drive home, hyped up from the caffeine.

As I connected my tube feeds for the evening, immense gratitude replaced my bittersweet regret. When I'd asked my family for help, they had come together, done what was right for Dad. Now I realized that they'd also done what was right for me: They had relieved me of the heavy burden of caring for my dad when I could no longer manage it.

If my health problems hadn't prevented it, I would have cared for Dad for the rest of his life. As it turned out, during his final months my sister's kindness and joy were just what he needed.