The Quiet Work of Dying

Category: Stories
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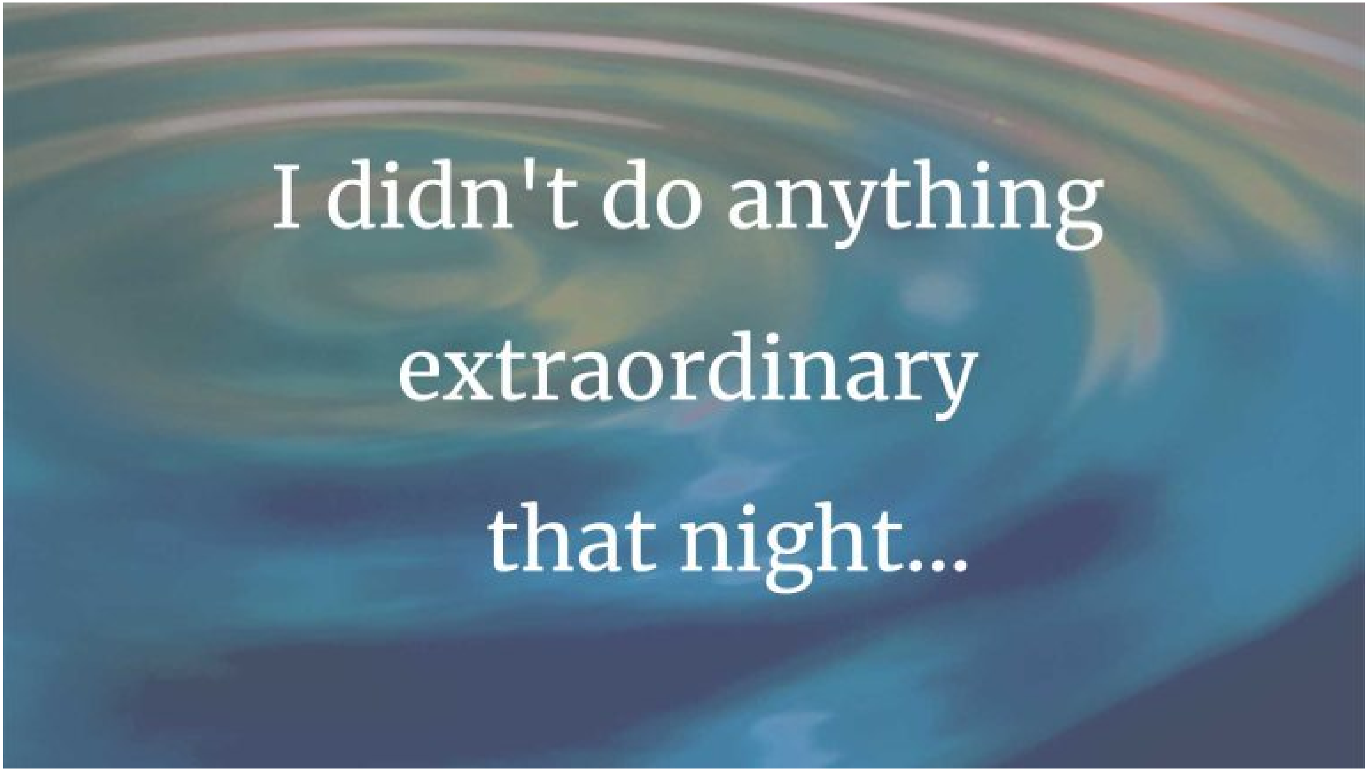

The first thing I remember is the sound of oxygen at night.

It was my second week as a hospice nurse. I had just pulled up to a modest home on a cul-de-sac, the kind of place where wind chimes echo off empty sidewalks. Inside, a man in his seventies was dying of end-stage pulmonary fibrosis. He was surrounded by family, but it was that soft hiss—steady and rhythmic, like an artificial tide—that centered the room.

His breathing was labored, yet peaceful. His wife sat beside him, holding one hand. I sat on the other side, barely touching the sheets. I didn’t do anything extraordinary that night. I adjusted his medications. I reassured his children that he was comfortable. I checked his vitals, even though we both knew what direction they were headed. And then I stayed.

We don’t talk enough about the staying.

Hospice work is often imagined as a kind of angelic labor—soft music, candlelight, a peaceful passing. Sometimes, yes. But more often, it’s kitchen tables crowded with pill bottles, middle-of-the-night phone calls, and the heavy silence that descends when someone asks, “How much longer?” and you honestly don’t know.

In my eight years of working in hospice—first as a field nurse, then as a manager, and then back in the field again—I have sat beside hundreds of deaths. Each one is its own kind of sacred. And each one, if I’m honest, took something from me. But it also gave me something I didn’t expect: a deeper understanding of what it means to live.

I learned to let go of the idea that I was there to “fix” anything. Death cannot be fixed; it can only be witnessed. It took me time to understand that *presence*—steady, grounded, human presence—was more powerful than any medication. I learned to hold a hand, to breathe alongside the anxious, to sit in silence without trying to fill it.

I also learned about systems. About how hard it is to deliver good care in a world obsessed with documentation. About Medicare audits, staff burnout and the emotional gymnastics of trying to achieve both compliance and compassion in the same shift. There were days when I felt like I was spending more time clicking computer checkboxes than sitting with patients.

Eventually, I moved into management. I thought, naively, that I could fix things from within. That I could protect my team. That I could make the system kinder. And to some extent, I did. I advocated. I mentored. I fought for schedules that honored work-life balance and grief support. But I also saw firsthand how broken the infrastructure really is.

Hospice is built on a shaky foundation—underfunded, overregulated and inequitable. I saw patients in wealthy suburbs receive daily visits while patients in rural or underserved areas struggled to get essential equipment delivered on time. I saw staff pushed beyond capacity. I saw grief, both personal and collective, brushed under the rug in the name of “resilience.”

There were moments when I wanted to scream—and others when I did, behind closed doors, where the grief had room to echo without consequence.

But I kept showing up. Eventually I returned to field nursing, craving the clarity of the bedside. I missed the closeness of those final moments, the profound intimacy of being let into a family’s hardest day. And I brought something new with me—a sense of integration between who I was as a caregiver and who I was becoming as a person.

Hospice changes you. It changes how you parent. How you listen. How you argue. How you forgive. After spending enough time in this work, you stop sweating the small stuff—not out of some saintly detachment, but because you’ve watched people die with regrets about the things they didn’t say. You start saying “I love you” more often. You start letting things go.

The boundaries between the professional and the personal blur in hospice. It’s impossible to care for the dying every day without reflecting on your own mortality. Without wondering how your own story will end. Without asking yourself whether the people you love know exactly how you feel about them.

Eventually, I began to write. First short pieces, then full chapters. I self-published a variety of different genres of books while I attempted to find my niche. And then a book—*Terminal Justice*—about inequities in hospice care, particularly for marginalized communities.

Writing gave shape to my fury. It gave language to the things we don’t say often enough in health care: that dying should not be a luxury. That comfort is a human right. That caregivers deserve systems that support them, not burn them out.

Now, I find myself back in a leadership role—one foot in administration, the other still firmly planted in the sacredness of bedside work. I speak at conferences. I train new nurses. I try to pass on what I've learned—not as gospel but as lived experience.

Here's what I know: The work of hospice is quiet. It rarely makes headlines. It's not flashy or heroic in the way we're taught to view medicine. But it is the most human work I've ever done. It asks everything of you—your presence, your humility, your endurance—and, in return, it gives you glimpses of life stripped down to its rawest truths.

I've held the hands of people dying with grace. And people dying with fear. I've watched reconciliations happen in whispers. I've sat beside wounds that had nothing to do with the body. I've cried in my car after a visit that shattered me. I've learned to say goodbye in twenty different ways, sometimes with words, sometimes with silence.

What I want people to know is that hospice isn't about giving up. It's about shifting the focus—from curing to caring, from quantity to quality. It's about showing up when others step back. It's about dignity, presence and love.

And yes, it's about rage too. Rage at a system that too often fails those who need it most. Rage at how hard we make it to die well in America. But it's a productive rage—a rage that fuels change.

I wrote my memoir to make the invisible visible. To honor the caregivers, the patients and the families. To challenge the policies that silence dignity.

And to say, as clearly as I can: This work matters. The people doing it matter. And how we treat the dying reflects who we are as a society.

So I keep writing. I keep speaking. I keep showing up.

Because if there's one thing I've learned from being with the dying, it's this: The most important things in life are often the quietest. The hiss of oxygen at night. The squeeze of a hand. The truth spoken at just the right moment. The presence of someone who stays.

Hospice taught me that.

And I'm still listening.