



Illustration by Steph Goss

Death with dignity: The collateral damage

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In retrospect it now seems weird that on Mother's Day Lily returned from tending her parents' graves, as was her routine for that observance, and said, "We need to make our final arrangements."

I said, "You know I want to be cremated and my ashes dumped in Puget Sound."

"Yes, but you know I'm deathly afraid of water because I can't swim. So that doesn't work for me," she replied.

"Okay, so where shall I put your ashes if you go first?" I asked.

"I want our ashes to be interned together at Bonney-Watson cemetery where my family all lie," was her request.

Made no difference to me, I'd be dead, so, I agreed.

She promptly arranged the purchase of our urns, cremation, and interment cubicle that we jokingly referred to as our Forever home. I wrote the check. Done.

A week later she suggested we update our wills, which we did.

The lawyer advised that since we don't have a safe, we should buy a waterproof/fireproof box in which to store our wills and other important documents. We obediently drove to Office Depot and bought one to slide under the island in our kitchen. Damn thing weighs 55 pounds.

A week later, while pulling the lock box from under the island, Lily strained an abdominal muscle. At least we assumed a pulled muscle was causing the pain.

Over the ensuing weekend the pain worsened. On Monday morning Lily—who hated seeing a doctor even though she married one—said, "I can't take this any longer. I'm going to ask if Michelle [our physician] can see me today." This was August 2.

Lily was seen at 10 a.m. that day.

Michelle scheduled her for an abdominal wall CT for 3 p.m. that same day. When the scan took longer than expected I asked Lily if she knew why. "The radiologist called Michelle to order contrast," she replied.

At that moment, I knew we were in serious trouble.

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Michelle was supposed to call us that evening with the CT results but didn't. My worries increased.

The next morning, Michelle called to say Lily had primary liver cancer with metastases in bone and gut. She'd ordered a CT of the chest for that day, Tuesday, August 3, again at 3 p.m.

In the universe of news, learning that the chest CT was clean should've felt good, but it rang hollow. Michelle scheduled an MRI of the head, but I refused to subject Lily to that claustrophobic confinement, opting instead to go straight to tissue biopsy. I figured it was academic at this point if the tumor was also in her brain.

The next week, the oncologist gave us the bad news: Lily was too frail for chemotherapy and would be placed on hospice care. In other words, go home to die.

Lily began rapidly spiraling downhill, without appetite or energy, and with progressively severe depression. She was dying and knew it. There was little I could do but support her—mentally and emotionally.

In January 2011, Netflix released the documentary, *How to Die in Oregon*. In 1994, Oregon became the first state to legalize a terminally ill person's request to end their life with medication. At the time, only Belgium, Switzerland, and the Netherlands had legalized the practice. *How to Die in Oregon* tells the stories of those most intimately involved with the practice—terminally ill Oregonians, their families, doctors, and friends—as well as the passage of a similar law in Washington. Shortly after its release, we'd watched the film and periodically discussed exercising that option if faced with terminal disease.

I'd seen my mother endure a prolonged miserable cachectic death in a nursing home bed from widespread metastatic cancer and had wished then for a more humane option to end her suffering. My sister too died of cancer. She had opted for the death with dignity but was physically and logistically unable to negotiate the required byzantine hurdles. Because of these experiences and our prior discussions, we began the process to allow Lily this option.

Death with dignity requires an understandably long complicated process of paperwork and effort. A list of required official forms that need to be completed include:

1. A Request For Medication To End My Life In A Humane And Dignified Manner form signed by the patient and two witnesses at a time the patient is deemed mentally competent by a licensed mental health professional;
2. Attending Physician's Compliance Form;

3. Consulting Physician's Compliance Form; and
4. Psychiatric/Psychological Consultant's Compliance Form to document the patient's mental competency.

Before the prescription for the life-ending compound can be written and filled, the patient must make a second formal request to the attending physician at least 15 days after the first documented request, and, again, be shown to be mentally intact at that time.

Only two pharmacies within the greater Seattle area fill such prescriptions.

Not surprisingly, the cost of the medication is not covered by health insurance, at least not by ours, and, of course, it is expensive (\$700 in our case), automatically eliminating this option for a financially strapped individual.

Between the time of Lily's first and second formal requests to end her life, a compassionate volunteer from End Of Life Washington visited our apartment to explain in great detail the steps for administering the drugs. This description was, as it turned out, extremely accurate and detailed.

At 7:00 p.m. on Friday, August 27, I had the medications delivered to our condominium so they would be on hand when Lily wanted them.

At 8:00 a.m. on Saturday August 28, only 24 days from the time of diagnosis, while straining at a bowel movement because Codeine constipated her, Lily was struck with severe abdominal pain, screamed out, and doubled over on the commode. I heard her yell and ran to the bathroom where the aide was attempting to comfort her. Crying, she looked me in the eyes and said, "I can't take this any longer. I want to die."

I asked if this is what she really wanted or was it a reaction to her acute pain.

"Yes, it's time. I want to die. I want to get this over with," she told me.

I could tell she meant it.

I called our End Of Life Washington support person and then Michelle. I had Lily take the preparatory medications on the requisite empty stomach to keep her from vomiting up the foul-tasting concoction of morphine and other drugs that would end her life.

By 10 a.m. both the End Of Life Washington volunteer and Michelle were present. They dissolved the medication in about an ounce of water, poured it into a short glass with a short straw. Lily and I have no family, so I was her only loved one to comfort her in these final moments.

We lifted her to a sitting position in our bed and

Michelle once again affirmed the consequences of what she was about to do. I held her frail body as she drank all the medication. We gently laid her back down and I held her, repeatedly telling her how much I love her.

The volunteer and physician respectfully left us alone to walk this final path. One that I will never forget.

Lily complained that the medication made her ears hurt. No one can explain why.

I told her the pain would end soon.

When she slipped into unconsciousness four to five minutes later, I felt relief in knowing her emotional and physical pain were finally over. But her heart continued to beat, making her officially still alive.

I continued to hold her another 40 long minutes as the remnants of life slowly ebbed away, the length of time atesting to this courageous and vibrant woman's strength. Those last minutes were excruciating for me.

The End Of Life Washington volunteer phoned Bonney Watson mortuary for me and then she and Michelle left. I held Lily's hand, wondering where she was now, dwelling on the questions early religious teaching instill in us regardless of one's later faith, or lack thereof.

Lily's shrouded body was wheeled away 45 minutes later. The morticians left a single white rose on the bed where she'd lain. I broke down emotionally at the sight of it. The memory still provokes that emotion in me.

Collateral damage

As our front door closed behind the morticians, I assumed the worst part of Lily's death was behind me, that I should focus on dealing with my grief for however long it would take to burn down to a manageable level. Little did I anticipate what would happen next: flashbacks. Not just a fleeting memory or two, but full-blown vivid life-like memories of moments lying beside her, holding her hand, feeling her grip lessen until one final spasmodic grasp a minute or two after she had apparently slipped into a deep coma followed by 40 minutes of intermittent agonal gasps until a final silence. I still relive excruciatingly vivid memories of her death for 30 seconds to one minute during these episodes.

I wish I'd been warned of this potential side-effect when Lily was told what to expect during the process, but I wasn't. Perhaps—I've since learned—because no one from End Of Life Washington has heard a survivor complain of flashbacks. Perhaps I am an outlier, a one-off, an anomaly, but I doubt it. Perhaps, that question simply has never been asked of support group attendees.

Over the six months since her death, these flashbacks

are thankfully finally beginning to subside in intensity and frequency, but I still agonize daily over what must've been going through Lily's mind as she swallowed and then waited for the compound to carry her away.

I sought grief counseling from a psychiatrist shortly after receiving Lily's diagnosis. She's helping me cope with this, as does the Xanax I take, and so will time, I hope.

What's the point to all this? It's certainly not intended to criticize Washington's Death With Dignity law or the compassionate work of End Of Life Washington. This law allows terminally ill patients an option to control their death with dignity rather than endure the lengthy and demeaning suffering my mother and sister were forced to experience in their final days and hours. The volunteers who assisted Lily did so in a caring, sensitive, and extremely ethical manner. They were terrific.

I just wish part of the effort could be proactively directed at preparing survivors—especially a devoted spouse who assists in the process—to deal with the very real emotional aftermath that can result.

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