Luminous at the end: My sister's last 40 days

by Anthony B. Robinson in the June 10, 2015 issue

Sunset behind the bridge to Whidbey Island, Puget Sound, Washington. Photo from Thinkstock

From the Wednesday in mid-July when my sister called with word of her illness to the bright Sunday afternoon in late August when she died, death was a revelation: it put everything else in a different light. In a culture where we control so much or believe that we do, death is not ours to control. And in the end, there was something more: a luminosity.

It was 40 days from the day my sister Regan called to tell me that an MRI had revealed metastatic cancer in her liver, lymph glands, lungs and brain to the Sunday she died. Six years earlier she had been treated for breast cancer. It metastasized suddenly.

Were these 40 days a Lent lodged in summer? I tried that idea out as I sat alone a few days after her death, trying to make sense of the experience of the past five and a half weeks.

During those weeks there was mourning going on, of course. Mostly the mourning was that of friends and family. My sister seemed remarkably serene. But our 40 days were more a time of being awake, of being alert in the best way. Perhaps it was what Lent ought to be, what it was intended to be? We were not giving up tokens of life, like chocolate or television, we were surrendering a loved one. We lived those 40 days at an edge, a boundary. Death was intersecting life, revealing us to ourselves.

I had stopped working two weeks before my sister called with her shattering news. My retirement meant that for the first time in nearly 40 years there was nothing on my schedule requiring my presence.

And yet it was clear from the moment she called from a hospital room in Everett, Washington, that my presence was required. It was not a burden, but a summons and a grace. My sister's son and I would be her primary care team for what time she had. Doctors said that time might be anywhere from three weeks to two months.

When this news arrived, my wife and I were at a family cabin in a remote part of Oregon. I left before sunrise the next morning, driving across Washington State, to Whidbey Island in the Puget Sound. My sister had purchased a small home on the island a year before, for her own retirement. She had planned to retire from a career as a librarian and library administrator that August.

As I drove through the Yakima River Valley, passing vineyards and orchards, I recalled a seminary discussion about death. "Most people today," said the professor, "say they prefer a quick, even a sudden, death—a heart attack or a massive stroke. Here today, gone tomorrow. No lingering, no extended suffering."

"But in earlier time," she continued, "it was different. Premoderns actually wished for a time of dying. They preferred a time of illness." Such a time is necessary for a good death. It allows the dying person to prepare, to put one's house in order.

The tasks of the dying are four: to tend to one's worldly affairs, providing if possible for one's dependents; to make amends, to receive and extend forgiveness; to seek peace with God; and to say goodbye, to hear and to speak last words. Doing these things constituted "a good death."

For my sister, surgery was mentioned as a last-ditch possibility. It might buy some time. She chose not to pursue this or any other treatment. In fact, she didn't even stay the night in the hospital where she had been admitted for the MRI and exam. After the diagnosis was confirmed, she said to the friends with her, "Let's go home." They got back on the ferry, went home, and ordered Thai take-out.

Perhaps one of the reasons that people today prefer a quick death is that modern medical practice makes it difficult to die. Instead of turning to the tasks of a good death, the sick are either isolated in a hospital or are sent back and forth to a hospital or clinic for this or that treatment. Sometimes the treatment works. There's a remission. But often it seems that it is not so much living that is prolonged as dying. Even then death itself may not be much reckoned with; the focus is all on staying alive.

With no earthly hope, my sister was spared all that. Her dying was remarkably free of medical interventions and institutions, of doctors and drugs. She was at home for those 40 days. We had the support of a nonresidential hospice program. After her diagnosis in mid-July, she never saw a doctor again.

It wasn’t that she had anything against doctors or modern medicine. They just weren’t needed. In hindsight, the absence of doctors, hospital, drugs, and efforts to sustain life at any cost was crucial to these 40 days being such an extraordinary time.

For the first week of the 40 days Regan was devoted to putting her affairs in order and making necessary preparations. She made a trip to a lawyer to review her will and met with the financial planner who managed her modest assets. Arrangements were made for her house. She wanted it to be a place that family and friends could use for vacation and retreats on the island. And we had visits from each member of the hospice team: a nurse, a social worker, and a spiritual counselor (who was a Buddhist priest). Last on her list for that first week was locating a mortuary and making arrangements for after her death.

While I am no stranger to mortuaries, that visit was hard. A day or two later a friend took me aside and said, “I asked Regan if the appointment at the funeral home was difficult. She said, ‘No, because Tony was with me.’” Tears of gratitude.

At the mortuary, I surprised myself and my sister, when I told the staff member I wanted to be there at the time of the cremation. The mortician took it in stride. “That will be fine. You can even push the button to begin the cremation, if you wish,” he added. It somehow sounded as if I were being invited to participate in a rocket launch. “Probably not, but thank you.”

In the evenings, we had parties. Every night friends on the island came for drinks and dinner. My nephew, a chef, cooked. We sat on the deck overlooking a tidal estuary on Puget Sound. We watched as northern harriers, a type of hawk, made their banks and turns. Cedar waxwings hunted berries. Red-winged blackbirds hung like flags on the pussy willows. Swallows had made my sister’s home their own. We drank wine and ate leisurely dinners as the long evenings of a Northwest summer unfolded. We listened to ball games on the radio, read poetry, told stories, and hugged a lot. Some evenings Regan would announce, “Time to go, I’m done.”

If it is odd to have parties when someone is dying, it didn’t seem that way to us. We needed to be together. Summer was still beautiful, perhaps even more beautiful. I did wonder sometimes if the frivolity was some type of denial. Maybe, but mostly it seemed to be a matter of enjoying the time we had with people we loved.

This was made easier by how slowly my sister declined. It was not until the last three days of her life that she was bedridden. For the first four weeks she was up early, listening to the news and writing notes to friends. She took short walks in the afternoon or evening as long as she was able. She welcomed company. Every now and then she would have some task at the house that she needed our help with. She rode along as we made the usual weekly trips to the dump and recycling depot. We made more trips than usual to the thrift store, dropping off things that she was no longer going to need.

Something of which I was immediately aware was this: with my sister’s death, my own family of origin would be gone. She was my only sibling, two years younger than I. Our parents were both deceased. My mother had died not quite two years before at the age of 94.

One evening, when my nephew was away, the two of us went out for dinner at a quiet restaurant with very slow service. That was good, it allowed plenty of time to talk. I worked up my courage to ask a question about our mother, a somewhat difficult person.

“Do you think,” I asked tentatively, “that Mom wanted children?” My sister surprised me by laughing out loud. “No, of course she didn’t want children,” she said.

She went on to tell of working on a college assignment, “one of those autobiographical things, before you have anything to say.” She interviewed Mom for the paper. “No, she hadn’t wanted children—it was what you were to do.” More information: “She was glad, though, that she had you first—a boy—got that out of the way.”

And later in the conversation: “All the pressure and expectations were on you . . . I just had a good time.” For me, it was an important conversation. It confirmed what I had felt, and struggled with, much of my adult life: my mother was a diffident and distant parent. Now we could say it, even laugh about it.

It was probably not a conversation we would have had apart from the circumstances of impending death. Soon this last living link to the home and family in which I had grown up would be broken.

We had other conversations too. In recent years we had discovered that we had, in many ways, been on parallel paths: she in the world of the public library, me in the church. Both of us loved the institutions we served. Both of us engaged in lover's quarrels with them. We both waged sustained campaigns to get the institutions we cared about to adapt to huge shifts in the culture. There had been no overt push or direction from our parents toward a vocation that might be termed "the pastoral care (with a little prophetic challenge thrown in) of institutions," but we had turned out to be two peas in a pod.

My sister's home was on two levels. It had two bedrooms and a bathroom downstairs, with a newly completed outside deck. Upstairs was one large room that tripled as kitchen, living, and dining areas. Outside there was a larger deck. As the days passed she found it more difficult to climb the stairs. A week before her death was the last time she was able to go upstairs. She made the transition from the house's upper deck to its lower one without complaint, only marveling at the new cedar deck on the lower level. It allowed her to sit outside, continue watching birds, and welcome friends and family.

Meanwhile, the resources provided by the hospice agency were coming more into play. We had been using morphine for pain for about two weeks. In that last week, we switched to the more powerful methadone. Breathing became difficult for her. She just didn't have the strength required, a strength you don't think about until you don't have it. Oxygen was brought in not to keep her alive but to keep her comfortable. At first she used it for short periods, but these gradually lengthened. For the last three days she was receiving oxygen full time. In her bedroom the oxygen machine made a sound like that of a small drum, a whop followed by a soft whoosh, every ten seconds—its beat a herald of death's approach.

At the time of the MRI, a young neurologist had forecast my sister's dying: she would develop a headache, go to bed, and die in her sleep. That sounded good. She watched and waited for "the headache." When we related this prognosis to the hospice nurse, she said that while that did sound good, she had never actually seen it happen that way. More likely, she said, you will be in bed more and more, you will not want to eat, your body will shut down, you will stop breathing. And that's how it went.

The final three days, she was in bed. "No more visits," she instructed. My nephew and I were joined on weekends by her best friend, Rhoda. So it was the three of us with her, with each other, for the very last days. We took turns sitting with her, sometimes reading to her. She laughed aloud as Rhoda read essays of

E. B. White one evening. Every now and then she would shoo us all from her room, asking us to put on the news on NPR or music. Two days before she died, she told us, "I want to die." I said, "It's OK, you've done what you needed to do. I love you. We love you. You can go."

The last morning, a beautiful sunny Sunday, her breathing was hard labor. I heard what pastoral work had taught me to know as "the death rattle." We held hands. We prayed. Shortly after 1:00 p.m. it was over. I understood then why people speak of death as "passing away." It was as if she had passed away, the precise instant of death unclear, as she passed from this life to what lies beyond.

The three of us held one another, then parted, each to grieve alone for a bit. Initially, I was dry-eyed and numb, but then I was suddenly overcome in ways I did not anticipate but welcomed. I wept uncontrollably. After a time, we came together again, opened a bottle of Prosecco, and drank a toast to Regan. Calls were made. Someone from hospice would pronounce death. Later the funeral home people would come.

Rhoda said that she wanted to prepare my sister's body, washing and dressing her. Neither my nephew nor I offered help: we left that work to Rhoda. I thought of the women going to the tomb to attend to Jesus' body. No men. When Rhoda was done, my sister wore a lovely dress and her hair was combed. The struggle of her final breaths had vanished from her relaxed face. Her hands were folded around a small bouquet of her beloved sweet peas—lavender and pink.

The 40 days of Lent are not the only such 40-day period in Christian tradition. There are Moses' 40 days on Mount Sinai and Jesus' 40 days in the wilderness. When Moses returned from Sinai, his face glowed with God's presence. It shone so brightly that the Hebrew people asked him to cover up—he was just too bright.

During her last 40 days my sister had what I can only call a brightness. She had always had a radiant smile. It did not leave her. A handsome woman, she seemed to grow more so as those days passed. But the light of those days was not only hers. It was as if the whole time, the whole journey, were made in some light.

A terminal diagnosis is a tough hand to be dealt. But in another way, my sister and we who were with her had also been dealt a good hand. There was time, but not forever. There was home and friends, not a hospital. There was support, but not debilitating treatments. It was, in this sense, a good hand, and she played it well. She tended to what needed to be done but didn’t fret over things that couldn’t be done or didn’t need doing. She accepted her coming death but was not preoccupied by it. While she never surrendered her own power, she did allow us to care for her. She told us what she wanted and what she didn’t want.

Perhaps most important of all, she did not do what I have sometimes seen the dying do: push others away. Whether in fear or anger, dying people sometimes do that. Regan did not. There was a richness to her dying, a revelation in death. We too had been to some mountaintop, and our own faces too shone from the journey.