



## THE ART OF DYING

Hospice professionals provide a bridge for the terminally ill and their families.



I knew working on a story about end-of-life care that some of the people I talked to might die. I didn't think one would be my father.

## We all have to deal with death. What we can learn from those who do it for a living.

Do most still wait until it's too late to prepare for the end?

**Jeff Schwaner, Staunton News Leader** Updated 9:32 a.m. EDT Sep. 30, 2019

I headed to Rhode Island, aware that my father was likely to die before I reached him.

Nine hours through five state borders, with two still to cross. To the edge of a border I would not be able to follow him through.

A "Welcome to Connecticut" sign floated by. Almost there. I needed coffee, I needed a restroom break, my car needed gas, but I was afraid to stop.

Driving my dad's old Explorer, I felt memories stream by and fade in my rearview mirror like the cars I was passing.

A scene from a few weeks earlier kept me calm: It's a quiet night at Dad's nursing home in Rhode Island. It's built on top of a hill above the signature small blue lakes that dot the northern part of the state, surrounded by pines and oaks.

I sit beside my father's bed, my hand resting lightly on his hand as he sleeps. The room slipping into dusk. The only light the flat-screen TV showing the Red Sox game. The game is on almost every screen in the nursing home.

Dad wakes quietly and smiles.

He squeezes my hand and we talk about how good the Yankees are this year. "I'm so glad you're here," he said. Making no effort to say goodnight or to let go of my hand, he closes his eyes, still smiling.

I realize it's the first time I have ever seen my father fall asleep.

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## **'Help them have a good death'**

"You know, I've done this for a long time," Jody Warwick said from her porch in Augusta County near Sherando Lake. We were drinking iced tea on a hot June day as wasps bounced off the front porch posts.

"I've been a hospice nurse since 2009," she said. "A lot of people won't pass away until they have closures, whether it be a loved one come in from out of state, whether it's talking to somebody on the phone. So, you know, if somebody is lingering, we try to find out: What's the reason? Is there somebody they haven't seen?"

Warwick has witnessed thousands of lives end. How do so many deaths affect you after 10 years? She's in a profession where even in the best circumstances a relationship with a patient ends with them dying.

She took a minute to answer. "Part of being a hospice nurse is, you know, to have this ability to compartmentalize. So when they're gone, I can remember them affectionately, but I try not to remember too many details. Because it can be overwhelming."

So can the statistics. Hospice caregivers at Augusta Health helped more than 800 people and their families last year prepare for death and navigate their final days.

In the two months that passed between conversations with Warwick, over 100 hospice patients have died. In that same time the daily count of patients in hospice care has gone up from an average of 178 to 200 people.

At a height of over 6 feet, Warwick is a hard person to miss. She just completed the August training session for hospice volunteers, where she patiently walked a dozen

trainees through the proper steps of helping a person out of a bed to a wheelchair, from a wheelchair to a walker, from a walker to a portable toilet.

But she has been missed, in a different way. Missed by a client at Shenandoah House, where she's the head nurse. The patient hadn't seen her for a week.

"I took a little vacation," Warwick explains.

"I'll take mine later," Geneva Wimer says quietly, punctuating the thought with a small grin.

For a moment Warwick and Wimer gaze at the flower beds maintained by volunteers and talk about Wimer's pets and family.

"You're blessed," Warwick tells her. She's seen patients who do not have the support of a large family. She's been with patients who would have died alone if she were not there.

"I know that," Wimer replies warmly. "We had all kinds of family here, didn't we?"



One of the volunteers who maintains the flowers outside was at the morning training session.

He came up to me just after the trainees had tried on the masks they must wear for immuno-compromised patients.

While the practical side of the training is vital, “It’s really so much about listening to people’s life stories,” is the first thing he told me.

“Knowing how to leverage your body weight to help a person get out of bed isn’t a bad thing, either,” I said, thinking about my recent trip to see my father.

As I watched the exercise continue, one of the trainers asked me if I wanted to try on the mask. You have to put it on a specific way, pinch it over the bridge of your nose to create a peak, and pull the bottom part down past your chin so it covers both mouth and nose.

“No thanks,” I said. “I have had plenty of experience using that.”

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I had traveled to New England in early July to spend a few weeks with my father, who was diagnosed with a terminal blood cancer while I was in the middle of researching hospice care for this story.

I was sitting on the edge of his bed, adjusting my mask, feeling stupid and a little claustrophobic breathing through it. Eventually I gave up and pulled it down beneath my nose so I could breathe.

“Nothing hurts, Jeff,” my dad was saying.

That wasn’t exactly true. Since his first trip to the hospital when he was too weak to walk to the bathroom, he’d been attached to a catheter. It was uncomfortable, sometimes painful. It created additional risk for infection while also being a psychological and physical impediment.

Every time he moved, or was helped in and out of a wheelchair or a car, one end of the catheter had to be moved with him, carried or clipped to the wheelchair’s bottom. It was more painful and deflating to his sense of self than the thing that was killing him.





Still, it would be fair to say that he looked worse than he felt. His arms were a checkerboard of bruises from constant blood tests and transfusions. Because he'd been on a blood thinner after heart surgery, he bruised easily.

Because he was immuno-compromised, all visitors to his room including family had to wear masks.

My father had always been the one who did things — he coached all my little league baseball teams, he was the president of the Cumberland-Lincoln Boys Club, he designed industrial parks and recreational areas. Ideas he got involved in became things that happened.

Now he was stuck here in a bed, bewildered.

At times, as we sat together, I would catch him counting his fingers, lips moving silently.

“What are you doing, Pop?”

“Nothing.” Going back to the counting.

One time I counted along with him in my head, and realized he was counting to 90. My dad, a month shy of his 86th birthday, the only one left of his generation in the family, was counting how long it would take him to outlive his own mother, who’d made it to 89.

When I told him I knew what he was doing, he smiled and looked back at me.

“Oh yeah?” he said.

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“At first I thought I was surrendering to death,” patient Colleen Cook told me over the phone in early June, about four years after she was faced with multiple terminal diagnoses giving her little chance to live through 2015.

One day she’d found herself painting a vibrant portrait of a woman laying on a rolling landscape beneath the sun. Waves of light seemed to become the waves of the hills, echoed in the shape of the woman’s body. She titled the painting “Surrender.”

“But when I finished the painting it seemed very full of life. Perhaps it is about surrendering to both.”

It would be easy to characterize Cook as a fighter, battling lung cancer, cancer in her spinal fluid, and cancer in the sac surrounding her heart. She chose to have dangerous brain surgery four times, as well as whole brain radiation with its severe side effects. She was willing to be a guinea pig for an experimental cancer drug.

Colleen Cook wanted very much to stay alive.

However, she was quick to dispel the fighter metaphor. She was not in a duel with death, she said. It was more of a duet, where she was trying to learn her part.

Colleen enlisted her long-time friend, Willow Kelly from Staunton, to help her arrange her final months. Caregivers in hospice range from volunteers to paid caregivers to nurses, social workers, chaplains, as well as the patient’s primary doctor. Together they work to implement a care plan with the client’s comfort at its center.

Kelly, an independent caregiver from Staunton who also works with Hospice of the Piedmont, helped Cook convene over a dozen of her friends and family to plan her memorial service and confront the inevitability of her death.

“Everyone deserves that gift,” Cook, 51, wrote in her journal. “To know their imprint and legacy. And to tell others how they have impacted us.”



Her fears had less to do with dying and more to do with how her children would get along without her.

In early June when we spoke over the phone, Cook was under no illusions that a magic pill would cure her.

She did not hide the fact that she was in constant pain but talked about pain as a teacher. She was eager to actively experience every moment she had left, including this conversation with a stranger.

“I really only have today for sure,” she wrote after we spoke. “We all know this is true, but I am living every day with this reality... I am living my best life, and I am dying.

“For right now, I am appreciating the trees outside my house. They are beautiful. I can smell lilacs from next door. The weather is perfect. A good day to be alive.”

As a caregiver Kelly felt uplifted by Cook, while also feeling the burden of guiding her. But that's her role. “It's to help this person fully live until they die,” said Kelly. “And to help them have a good death, whatever that looks like for them.”

## **'I'll exist as long as I exist'**

Everything was going too fast.

“This is my mobile office,” said Laura Summy as she negotiated the curvy two-lane road to Swoope a little over the speed limit.

Bins in the RAV-4's backseat held first aid supplies, gloves, pens and paper. In the wayback were packed oxygen and incontinence supplies and plastic tubing. A laptop and phone sat charging on the seat behind me.

“If I cared to,” Summy said, yanking the car hard right off the two-lane highway and onto a steep road running a ridgeline, “I’ve even got the ability to plug in a crock pot.”

On one side of the car trees filled with darkening August leaves climbed the hill. Pastures spread across the deep valley below.

If the RAV-4 is Summy’s office then her office view is beautiful and ever-changing.

Same for the work she does. It’s also private, and to have a reporter and photographer tag along she needed to schedule a special day for clients who’d invite strangers into their homes at a critical time in their lives.

A time when they are dying. Summy’s been a hospice nurse for five years.



We parked in a driveway off the rural road. She adjusted her modest lavender dress and her traditional Mennonite headscarf, and got to work.

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“What are you thinking, Pop?” I asked my father on the phone in early June.

He sighed. “I’ll exist as long as I exist, I guess.”



He was tired and weak. His body was not making enough blood, and his white blood cells were in short supply to counter infections and viruses. He was receiving twice-weekly transfusions and platelets.

A week later we found out the cause.

The diagnosis of rare myelodysplastic syndrome came down to a simple sentence.

“You’re only alive because of other people’s blood,” his oncologist stated from his hospital room in Providence as I listened on my sister’s phone. Chemotherapy might buy him some additional months, but it would open him up to infections which could kill him sooner.

My brother was pushing for chemo. “What do you have to lose?” he said. My sister, who’d hosted my father for seven years, could not give her opinion. She put her phone on a table and left the room.

“Jeff, what do you think?” my father asked from 567 miles away.

This had happened suddenly.

Nobody thought that he was looking at the last months, or even weeks, of his life until the diagnosis.

I answered my father as directly as I could. “If I had to face that diagnosis right now, I would not let chemo kill me. I’d make the best of the time that I had with my family.”

“I think I want to think about this,” my father told the doctor.

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The night before she first talked to The News Leader about her profession, Laura Summy was helping McKinley Burke die.

“The night he passed away,” McKinley’s wife Helen Burke said, “she made the time. Her day was done and she made the time.”

The Burke household is no longer on Summy’s weekly rounds. She’s stopping in to say hi to Helen, who’s agreed to talk about the experience of having a loved one die under hospice care.

Hospice care can continue for months after a person’s death. It focuses on the whole family and offers counseling services for family members after a loved one dies.

Helen Burke’s in-law apartment behind her son’s home is clean and bright. Other homes Summy’s visited are not so tidy. Summy’s learned over time that her sense of “normal”

must be left in her car with the other supplies when she visits a client. Her job, she says, is not to project a sense of how she thinks a client may be most comfortable, but to adjust herself to what is comfortable for the client. That may be a messy or chaotic or noisy household.

When a person dies at home, even a tidy house is not without the chaos of memory.

Helen Burke knows which chair her husband favored when the grandchildren paid their visits. She can still hear him asking her to “make him a bowl” of something she was cooking for a social gathering or outing — after he’d taste-tested it first, of course, she said.

So much about hospice care seems to be about stories. Everybody involved in hospice, including volunteers, are trained in active listening skills. A client may communicate more with their stories than answering direct questions, especially near the end of life, and hospice caregivers are attuned to that.

McKinley Burke told how as a boy he would go with his grandfather over to Goshen to pick up moonshine. He explained the pre-internet idea of fun his friends and he once engaged in — setting hay bales on fire. Burke notes this was a story their grandchildren particularly liked.

“Some of those stories he told, I had no clue,” said Burke.

She remembers a day when her husband had Summy taste-test her homemade rice pudding.

“I never really tasted my food as I was cooking it. I was used to him doing it,” said Helen Burke. After her husband’s death she found herself in the kitchen cooking one day, saying out loud, “I lost my taster. Doggone it, where is he at?”

As Summy got ready to leave, Burke half-joked, “I don’t want you coming for me, but I want you still to be my friend.”

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Among Summy’s other appointments for the day were Raymond and Jean Wilkerson, 94 and 92 years old, who were both on hospice but managing to live on their own in an old log cabin on the winding banks of the Middle River; and Herman Pullin, who’d been cared for by his wife at home since 1995, five years after an accident severely damaged his brain.

The Wilkersons’ property — and their entire lives — was connected to their road by a slim bridge crossing the river. On that bridge, barely as wide as her car, Summy would sometimes park after a visit to the Wilkersons. She’d turn off the car and open all the windows to hear the river passing beneath on both sides of her as she typed notes into her laptop.

Patients and caregivers at a crossroad in their lives. The medical industry at a crossroad in terms of how it works with the dying. By mid-June, in the middle of interviews for this story, I'd find myself at such a crossroad as well.

## **Finding peace with the dying**

I stopped by the house Dad built on Cape Cod and came back with a scrapbook my mother had made as the home was being built four decades ago. We spent hours one night looking at it.

When a family member is dying, sometimes the most peaceful place to be is with the dying person.

All around you are doctors, nurses, staff, family — and an endless swarm of questions. They float, weightless but threatening, like August wasps. Could we have foreseen this? What is the best way forward?

Even walking the dog unearthed more unanswered questions, it seemed.

One such walk turned into a discussion of the future of the Cape house. “There are hidden costs to keeping the house. The generator. Landscaping. And pest control,” my brother in law told me.

I found my peace sitting by my dad’s side, holding his hand and looking at photos, or watching a little baseball on TV.

During these visits, though, I noticed an indecision in my father I’d never seen before. He seemed a shadow at a distant gate, unsure himself which way he was going.

A simple fever one day sent him to the hospital again, where he spent four days. Hospital staff wanted to keep him longer. He was tiring of all the precautions.

On July 19, my father finally decided against chemotherapy. He’d stick with transfusions for the time being. At some point his body would stop accepting the platelets and his condition would deteriorate quickly.

After we talked to the doctors, I said my goodbyes to my father. I had to head back to Virginia. We stood for a while looking at one another across the bed.

“I’ll come back, Pop,” I said. “You just let me know and I’ll come back.”

Less than a week later, he'd let me know with a single word.

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The onset of what hospice nurses call active dying often involves a sudden burst of activity or energy by the person, including an increase in appetite and engagement with those around them.

Family can get a false sense of hope that a person is getting better, when they are actually preparing for death.

Willow Kelly saw it most recently with her client Colleen Cook.

Out of medical options, Cook was ready to die. Liver failure had set in, so chemo wasn't an option. Her strength was declining quickly.

Kelly arrived at Cook's house on July 5. Cook was at the car door instantly, insisting despite her weakness that she help carry bags into the house. The slight, almost pixie-like woman who'd somehow maintained a brightness despite her constant pain was, at the moment, incandescent.

"Load me up," she told Willow Kelly. Kelly tried to give her the lightest things from her car.

"Really, come on," Cook insisted. "Give me some more."

"She was relentless," Kelly said. She came back to the car three times to help. "And I don't even know how much walking she'd been able to do the month prior to that."

It was the last active thing she did. Now that she had her long-time friend and chosen death doula with her, her body had done its work, and she could let herself be taken care of. For the next three days she stayed in her bed with Kelly by her side.

Colleen Cook died July 8 just before midnight.

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Another sign of active dying: the dying person begins to speak in confusing and sometimes symbolic language, often holding conversations with people long dead or not in the room. This can be frightening and confusing to unprepared caregivers.

In the context of gaining closure, hospice nurses say, the talking can be a way to impart information to family members or friends.

My father's behavior took such a turn. He had a sudden appetite and ate more in a day than he had in a week before. He became extremely talkative. But what he said made no sense to my family.

He insisted that pest control had called him in his room at the nursing home. He asked my brother to move his tray away from his hospital bed so he could see the living room. My siblings worried about his mental health.

When I heard the words “pest control,” I knew my father was not out of his mind. He was in fact very much in his mind, at the house on the Cape. He had to visit it one more time, even if in his memory, to tell us what needed to be done to maintain it after his death.

He’d never said he was ready to die. But now he was covering the last details.

A few days later I received a call from my sister as I walked to my car near Lewis Creek. The doctor said that Dad no longer wanted transfusions, no more trips to the hospital, for any reason.

The doctor asked me if I understood.

“I understand,” I said, sitting in the Explorer and looking out over the rushing creek. “I just want to make sure that this is what my father wants to do.”

“He’s here in the room,” the doctor said. Silence on the phone. The creek bubbling by outside.

“Pop, is that what you want?” I asked.

My dad’s voice, the last time I would hear it, spelling it out: “Y-E-S.”

It was time to head back.

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When I arrived at the nursing home after the 10-hour drive, my brother and sister were by his bed. They both looked drained. Dad was breathing heavily through a dry mouth, and did not appear conscious.

When I held his hand and spoke to him, though, his head nodded my way. His thumb and fingers moved over mine as if identifying me by touch. It was 6 p.m. on Monday, July 29.

He had stopped eating and drinking a few days ago.

We sat quietly and watched him breathe.





A few hours in, I told the nurse I wanted my father's catheter removed. It had been a source of discomfort for him and I could tell from his movements that it was still bothering him, even in his half-conscious state.

It's not something I would normally do. There's a solemnity around observing the medical staff do their jobs, often tasks that they are sparing you from doing yourself. But if this was going to be the end, I wasn't going to let him die in unnecessary discomfort.

The nurse resisted at first, explaining that my father could not get up and go to the bathroom. I told her he wasn't going to be getting up again.

I stayed with him as the nursing staff removed the equipment and cleaned him. When it was done my father's breathing calmed noticeably.

I wouldn't have taken that step if I hadn't felt empowered by the caregivers I had spoken with back in Virginia. By what I had learned from them about active dying.

Around 10 that night, my brother and sister left for the evening. They both needed rest, and my father's condition had not gotten any worse.

I sat beside the bed as the room went dark, holding my dad's hand and keeping my other hand on his chest to follow the rising and falling of his breathing. It was a calming motion, like being brought up and back down by a wave.

I spoke to him at intervals throughout the evening. Sometimes I closed my eyes and focused on that motion of his chest, rising and falling.

Around 1:45 in the morning, the motion stopped. His body was still. I sat with him quietly, my hand on his chest for another few minutes as the finality of his death stretched into regular time going by. Then a nurse poked her head in.

“He’s stopped breathing,” I said quietly.

I kept the room quiet and waited another few minutes before I texted my sister that our father had died.



For a few days after I returned to Virginia I avoided parking near Lewis Creek because the memory of hearing my father’s last words there was too strong.

Without thinking one day I was suddenly on the shady path above the creek. At the head of the path a small stone bridge arches over the water.

I stepped halfway across and stopped. I thought of my dad, and of Colleen, the first person I met who made me think there really was an art to dying. I thought of Jody and thousands of hospice clients she’d seen. I thought of Wilkie and Jean Wilkerson and of Laura Summy and the bridge of trust she creates with each client and family.

I stood on the stone bridge and listened to the sound of water approaching, passing beneath me, and continuing on.