Alan Dickson’s Final Days
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How Hospice Helps | STORY BY ALEXANDRA BECKER | PHOTOGRAPHY BY CODY DUTY
— I —

Terrie Adcock, a social worker with Houston Hospice, settled into her favorite chair with a sigh. Outside her home, the March sky had grown dark, but she was not yet ready to call it a day. She pulled her computer onto her lap and inserted a flash drive filled with photos of a sprightly, 10-year-old Jack Russell terrier named Pal. Dragging her favorite images onto the desktop, she started building a PowerPoint, hoping it would end up in the hands of someone, somewhere, looking for a new companion.

— II —

Alan Dickson was dying. He was still living in New York when he suffered a series of medical blows—when doctors discovered the steady march of cancer spreading throughout his lungs, when a heart attack paralyzed part of his vocal cords, when he was diagnosed with congestive heart failure and diabetes.

In January 2016, Alan’s only living son, Brad, flew to Syracuse and begged his father to move out of his dirty, dilapidated home and relocate closer to family. It was a tough sell. Although he had mellowed over the years, Alan hadn’t shed his inclination to push away those closest to him. He liked being alone, liked taking care of himself, and didn’t enjoy talking about the hard parts of life. But Brad persisted, and a day after Alan was released from the hospital, father and son boarded an Amtrak bound for Houston.

“I didn’t want to push him because I know he’s very independent,” Brad said. “I didn’t want to say, ‘You have to move in with me,’” because that wasn’t my intention. But I needed to get him out of the toxic environment he was in.”

Alan moved in with Brad, daughter-in-law Grace, and their 6-year-old son, Matthew. Alan’s estranged wife, Carol, was also living in the house to help care for Matthew. Carol and Alan got under each other’s skin; they had separated more than 15 years earlier, because living under the same roof proved impossible.

Worse, Alan’s constant four-legged companion, Pal, was not welcome in Brad and Grace’s home due to a history of biting.

So in November, nine months after relocating to Texas, Alan moved into a small one-bedroom apartment in North Houston, where dishes piled up beside his desk and paperwork lived on a coffee table. Next to the couch he kept an old black and white photo of two children holding hands.

(continued)

Houston Hospice patient Alan Dickson with Pal, his 10-year-old Jack Russell Terrier, in front of his apartment in North Houston.
Clockwise from the top: Alan shops for groceries; Terrie Adcock, Alan’s social worker at Houston Hospice, goes over legal paperwork with Alan and his son, Brad; Alan with his grandson, Matthew, at an Easter egg hunt; Alan looks through old photographs.
The tiny girl in the jumper, his sister Gale, may have been the only person he didn’t keep at arm’s length.

Apartment 1513 was not a home, not really. There were no dents in the walls from rambunctious sons, no stains on the carpet from Super Bowls past, no memories of when his marriage was tender. But it suited Alan just fine. During the day, he would draw open the shades and sit in the sunlight to watch television, mostly shows about wilderness survival and living off the grid. Apartment 1513 was a place for him to crash, to drink beer or the occasional nip of Jim Beam, to buying Pal, a Tuesday bridge game and short trips to the supermarket. He often found himself over thinking about it.

Despite a full night’s rest—the first in weeks—Alan appeared exhausted when Terrie arrived. Despite a full night’s rest—the first in weeks—Alan appeared exhausted when Terrie arrived. They had been cornered by Matthew at the dining room table. He rattled off his encyclopedic knowledge of snakes and sharks. The Megalodon was his favorite shark, if extinct ones counted.

Terrie’s big news was that one of her colleagues had found a future home for Pal with a woman named Ann, a retired VA hospice nurse who summered on 20 acres in Washington State. Alan was pleased.

Brad told Matthew it was time to practice the piano and Carol ushered him into the front room. Terrie flipped through her paperwork, explaining in detail medical power of attorney and durable power of attorney.

“The other thing,” Terrie said, looking at Alan, “is that I really want you to have a medical alert system, so that if something happens and you can’t get to the phone, you have something around your neck or on your arm that will notify somebody that you’re in trouble.”

“I don’t know,” Alan said quietly. “I’m not too keen on it, but I guess it’s probably a good idea.”

“Why aren’t you keen on it?” Brad asked.

“I don’t know,” Alan looked down at his hands. “Is it a cost issue?” Brad asked. “You living alone I think it’s a great thing to have.”

“Yeah, probably should have it.” Alan did not look up.

Terrie interjected, “But what are your concerns?”

“He’s cheap. The money,” Brad answered. “And it’s probably acknowledgment, too.”

Terrie nodded. “This is all scary stuff. It’s a recognition that you are reaching a point where we at Houston Hospice have to keep a closer eye on you. You just keep getting more tired, and that’s all part of it.”

“We’re there to support you and you won’t be alone, you know that,” Brad said.

“And I think the backup plan is if he needs to come here…”

Alan interrupted Terrie.

“I’m not too keen on coming here.”

The conversation turned contentious. Brad’s voice rose above the pings of the piano.

“You can’t just push people away. We have to think about it practically.”

“So what’s the alternative?” Alan asked. He was barely whispering.

Terrie explained that, for the most part, the hospice team was able to manage symptoms in the home, but that caregivers were a critical part of the process. Sometimes, care could be arranged in an assisted living community. If inpatient care was required for severe symptoms, Houston Hospice had beds available.

Matthew skipped into the room. It was time for him to leave for swim lessons.

“Does anyone want a jellybean?”

“Say goodbye,” Brad told him, ruffling his hair. “Say it was nice meeting you.”

Terrie waved to Matthew as Carol shut the door behind them.

“At our next visit, we’ll have a really hard conversation about what end of life looks like and what your caregiving will have to be. Because you will reach a point where you cannot communicate. You will reach a point where you can’t take care of yourself, and we do have to make plans for that, OK?”

— TERRIE ADCOCK
Houston Hospice social worker

Karen Hoover, Alan’s hospice nurse, checks his vitals.
Alan said he was picturing Gale, who was currently under hospice care herself in California. His biggest fear, he said, was that he would end up like his sister: over-drugged, slurry and incoherent.

“I think it’s safe to say we really do a very progressive end-of-life medication routine,” Terrie said. “Our purpose, our goal for you, is comfort. OK? That doesn’t mean you have to be gaga.”

“Actually, I just want to die,” Alan said, looking at her.

“I know you do. We’ve talked about that. But you’re not suicidal.”

“No.”

“You’re just tired of the fight.”

— V —

By mid-April, showering had become difficult for Alan, sometimes insurmountably so. The worst part, he said, was putting water on his head and trying to breathe at the same time.

Father Raphael, the chaplain on his hospice care team, paid him a visit. Alan wasn’t Catholic, or anything for that matter, but he valued their conversations.

“I believe that we’re all connected,” Alan said. “We’re all a part of everything. Is there a God? Yeah. We are God.”

Alan’s hands shook as he squirted morphine under his tongue. He was taking a dose once an hour to ease his breathing and the pain knotted throughout his back. There was also methadone, gabapentin for peripheral neuropathy, albuterol for breathing, Senna and Colace for constipation caused by the pain medication, lorazepam for anxiety.

He was sleeping more each day and had all but ceased activity outside his apartment. Occasionally, he managed to take Pal outside, letting him roam as far as the leash would take him.

Alan and Brad talked in earnest. Alan did not want to be a burden in Brad’s home. He did not want to live under the same roof as Carol. He did not want his grandson to know he was spending all day in a bedroom, dying. So he was staying in Apartment 1513.

The vast majority of hospice patients—nearly 60 percent—are treated in the place they call “home,” which could be a private residence, a nursing home or a residential facility. Alan fit the hospice profile in other ways, too. Close to 85 percent of hospice patients are age 65 or older, and the same percentage receive services through Medicare, which started covering hospice programs in 1982.

Hospice was added as an optional benefit under Medicaid in 1986, but in recent years several states have proposed cutting optional Medicaid benefits, according to the National Hospice and Palliative Care Organization (NHPCO).

Although health care in America is poised for change under the Trump administration, the recent iteration of the American Health Care Act, released by Senate Republicans on June 22, would have a minimal effect on hospice care.

Both the Senate and House bills, though, propose deep cuts to Medicaid. Limiting the expansion of Medicaid could reduce the number of Medicaid recipients, said James Fauckett, president and CEO of Houston Hospice. The National Association for Home Health and Hospice voiced a similar concern about per-capita caps and the elimination of an important Medicaid option—the Community First Choice benefit—which encourages states to shift spending to cost-effective home care.

Perhaps the biggest threat to hospice care is increasing regulatory demands by the Centers for Medicare & Medicaid Services, said Jon Radulovic, vice president of communications for NHPCO. Increasingly, hospices must allocate already minimal resources to additional administrative efforts.

“Hospices generally have a relatively tight profit margin, so their operational costs are usually just covered,” Radulovic explained. “You don’t want to have to take dollars away from patient care for regulatory compliance.”

— VI —

A faded pair of black track pants sagged around Alan’s thinning waist. It was mid-morning on April 28, a Friday, and Alan was wearing his new medical alert necklace. He was un-showered; his skin sunken, his shoulders wilted with exhaustion.

Pal paced the room, growling at his Kong dog toy and nudging Terrie to play. She picked it up once or twice while she and Alan discussed his will and applications for an in-home caregiver she’d submitted through the VA and the Department of Aging and Disability Services. She said she was hopeful he would be able to stay in his apartment when the time came.

“Soon,” Alan said.

“You think it’s soon?”

“I think so.”

“Are you having more confusion?”

“Yeah, a little bit.”

Terrie said his oxygen would help. When it drops too low, she explained, the brain can’t function at capacity.

“I’ve been on oxygen all morning,” Alan said quietly. “Maybe I should go use it now.”

When he returned to the living area, he said he was ready to call Ann to come pick up Pal.

“It’s too much,” he said. “I don’t want to fight it; I don’t want to fight it anymore. My son fought it for six years.”

He found his cell phone and started typing on the keypad, then stopped abruptly.

“I’m losing it,” he said, under his breath. “I’m really losing it.”

“Are you OK?” Terrie asked.

“Yeah.”

“Do you think you need to get some rest?”

“Getting close to it.”

Alan tried typing Ann’s number again. “I keep forgetting what I’m doing.”

“You’re getting sleepy.”

“Yeah.”

Terrie helped Alan leave a voice mail, then led him into the bedroom where he settled in on his right side, facing the wall. She checked his oxygen and noticed that the machine was bone dry.

Without water, nothing had been flowing through the tubes—there was no telling how long he’d been without oxygen. Terrie refilled the machine and hooked up her patient. Alan closed his eyes.

A few hours later, Ann arrived and Alan got up to say goodbye to his best friend. He gave Ann an old sweatshirt with his scent on it and told Pal that she’d be his new mistress now. Alan was stoic. Although he was broken inside, he did not cry.

— VII —

Brad moved in to Alan’s living room with a large air mattress and his Maltese, Casey. By Wednesday, May 10, Alan was sleeping for the better part of the day, always on his right side, always under a red sleeping bag. His body had grown skeletal, his mouth slack-jawed. Each breath was accompanied by a constant gurgling rattle, a final stage of the body shutting down.

Karen taught Brad his father’s medication routine and the basics of changing diapers and urine drainage bags. In the absence of a hired caregiver, Brad had stepped in to honor his father’s wish to stay put. Through hospice care and family support, Alan would be at peace in his final days.

Over the weekend, he had experienced a surge, a common phase in the dying process during which a person undergoes a wave of clarity, hours or days before death. Terrie described it as a final gift to the family. Brad took advantage by setting up a Clint Eastwood movie marathon and buying ice cream. By the end of the day on Sunday, though, Alan had grown lethargic again.

“I feel like I’m running around like a chicken with my head cut off,” Brad told Terrie after returning from a quick trip to Wal-Mart. He unpacked bags of V8 juice, butterscotch pudding and sippy cups like the kind he used to give Matthew.

(continued)
From left to right, top to bottom: Alan at home in his kitchen; Alan and Brad watch movies in Alan’s bedroom; Alan’s medication sits on the kitchen table; Alan’s daughter-in-law, Grace, gives him water with a sponge; Father Raphael, a chaplain from Houston Hospice, prays over Alan.
“At some point, he will not be able to drink,” Terrie said. “You’re aware of that?”
Brad nodded.
“What about IV drips?”
“We don’t do that,” Terrie said. “Probably one of the hardest parts of hospice is when a patient doesn’t want to eat and the family thinks they’re starving them. And they’re not. At the end of life, that’s just a natural progression. When you’re sick, you don’t eat. And he’s very sick.”

Terrie asked Brad if Karen had talked to him about transitioning. When people begin to detach from life, they often see visions from the past and relive memories and conversations. The visions, Terrie said, start in the corner of the room, up toward the ceiling. By the end, they always move onto the bed. It’s a predictable pattern, she assured him, something every hospice worker knows well.

“There’s been a lot of talk about Selkirk, which is a place we used to go camping a lot as kids,” Brad said. “The other day he was acting like he was fixing a bike and it was the bike reflectors. … He thinks we’re actually there.”

— VIII —

The following morning, Alan tapped on the bed and called for Pal. Moments later, he was petting the air near the crook of his arm.
By mid-afternoon, Father Raphael had arrived at the apartment. Brad led him into the bedroom and showed him a wooden cross he’d found in Alan’s pocket. Alan tried to clear his throat.

A caretaker from the funeral home removes Alan’s body from his apartment.
“We’ve had a few very long and, to me, very rewarding conversations, just about your life and your journey,” Father Raphael said, leaning over Alan’s bedside. “We also talked about, in your own faith journey, how open you always tried to be to other people. And that when the moment came, you wouldn’t be averse to me praying with you and offering the consolation of the sacraments that I can offer to you. I hope that’s still the case, Alan. I thought I just saw you nod, but in any case, I would like to pray with you, Alan. May I pray with you, as we agreed, Alan?”

“Absolutely, Father,” Brad said, “Definitely, he’s OK with that.”

“He did let you know about that?”

“Yes, sir. I know he’s OK with that.” Brad grasped Alan’s hand.

“In the name of the Father, and of the Son, and of the Holy Spirit,” Father Raphael began. He spoke in smooth, soft rhythms, reading scripture and offering prayer. He asked Brad to help him with the rite of anointing. Brad placed his right thumb into an oil stock prepared with cassia, aloe and myrrh and traced the sign of the cross on his father’s head.

During the prayer, Alan mustered the strength to squeeze Brad’s hand.

— IX —

Karen arrived not long after Father Raphael said goodbye.

“He’s making a lot of noises,” she said. “Have you felt like he’s been anxious because of his breathing? Any distress? Because what I’m seeing looks very peaceful.”

“I think he’s at tremendous peace,” Brad said. “It makes me feel glad, because he knows that he’s here, he’s around love.”

Karen took Alan’s feet in her hands, checking for warmth. They were cracked and stiff and one was very cold. She explained that it was the body’s way of fighting for life, that it was doing all it could to shunt blood to the core.

Grace and Matthew insisted on spending the night. After dinner, the three of them piled onto the air mattress and watched a “Tom and Jerry” cartoon. Brad and Grace took turns getting up to check on Alan. Around 1:30 a.m., Brad woke suddenly, drenched in sweat. He slid off the air mattress and quietly opened the door to the bedroom, listening for his father’s labored breaths. The silence was deafening.

“Grace!” he whispered as loudly as he could. “He didn’t want to wake Matthew. He flipped on the light and saw that Alan’s dentures had popped out of his mouth.

Both he and Grace checked for a pulse. Nothing. Unsure, they called Houston Hospice and left a message with the answering service. Then, in a panic, Brad pushed Alan’s medical alert button. Soon the tiny apartment swarmed with flashing lights, paramedics and police officers. Carol arrived to take Grace and Matthew home. When the first responders learned that Alan had signed a DNR and was under hospice care, all but one officer left until an on-call nurse from Houston Hospice arrived to declare the time of death.

By dawn, a caretaker from the funeral home would wheel Alan’s body out of the apartment and down the uneven sidewalks. While Brad waited, he called his best friend.

“You know what your dad would do right now.”

“Get bombed,” Brad said, smiling. “You know, I think I could handle that.”

He went to the freezer and pulled out Alan’s handle of Jim Beam. He drew a few swigs from the bottle, then stood in the kitchen and cried.

Brad scatter Alan’s ashes in the water off Galveston Island, per Alan’s request.

Brad cleans the apartment moments after the caretaker leaves as a way of coping with his father’s death.