

FEATURE STORY

The Final Journey

BY KATHY LATOUR

For six months, contributing photographer Beatriz Terrazas and *CURE* editor-at-large Kathy LaTour met with the Abernathy family, documenting their lives as they traveled this final journey. This story is dedicated to them, for while it was Judy who invited us in, it was her family who opened their hearts to allow us to remain as they said goodbye to a woman whose life was inextricably woven through each of theirs as mother, friend, wife, or grandmother.

There is no perfect death or perfect family. Judy's choice to stop participating in a clinical trial was a result of her strongest wish—to die on her own terms while continuing to function as part of the family for as long as possible. We recognize that each death is unique, but our hope is that by providing a window on one death, the door will be open for others who face this time. This was Judy's wish.

✕ I am facing the end of my life, and I know it. I have accepted it. And I feel so blessed to have this time to prepare—and to prepare them. ✕

—Judy Abernathy

April

Since 2002 Judy has been living with her daughter, Christy Abernathy Green, 38, her son-in-law, Glenn, and their two sons, Brandon, 12, and Ethan, 7.

A Miniature Pinscher named Rusty announces visitors at Christy's spacious Dallas home, where Judy answers the door, eagerly inviting us in. As she leads us to the den, it's clear that her energy is low. Yet, the life force of this petite woman remains strong, evident in her fixed hair, manicured nails, and a voice full of inflection and personality. Judy knows she's in charge of her life—and her death.

Judy, or Nana to her family, settles into the recliner where she spends time when she isn't cooking or organizing herself or the family. She looks older than 64, but only the oxygen machine indicates the severity of her illness. Judy apologizes for her lack of energy, explaining she is still recovering from pneumonia. A life-long smoker, Judy was plagued with respiratory problems long before being diagnosed with inoperable, non-small cell lung cancer on July 19, 2005—ironically, her 62nd birthday.

Judy says she feels a sense of urgency; she senses that time is running out. “I don’t know how to explain it to you,” she says. “You can feel it. I can’t get my energy back as quickly. I just see little things, and I know that the time is getting nearer.”



Judy attended Ethan's last school assembly of the year to watch him get awards for reading and math. Photos by Beatriz Terrazas.

But there is more to do, she adds, and maybe telling her story is part of it. “If it would even help one person be able to get through this easier, then I will have accomplished something.”

Judy excuses herself to go to the porch, where she watches 7-year-old Ethan get off the school bus. Moments later, he bounds into the den to check out the visitors before he and Judy discuss the remainder of the day. With her “little man’s” arrival, Judy becomes more animated; the love between these two is palpable.

While Judy lives with Christy’s family, the whole Abernathy clan has begun pitching in when Judy has a bad day, which is happening more frequently since the pneumonia. Christy’s daughter from her first marriage, Heather Venrick, 19, often comes in from college, and Judy’s two sons live close by. Paul, 45, is married and has two children, Maigon, 18, and Garrett, 17. Danny, 43, is single and the father of 17-year-old Naomi. Both sons call daily, and Danny stays with his mother more and more frequently.

The family consumes Judy’s thoughts and hours. No longer able to attend church or sing in the choir, she gets visits from church friends, but it is caring for her family that gives her the will to live. “I am facing the end of my life, and I know it. I have accepted it. And I feel so blessed to have this time to prepare—and to prepare them,” she says.



Ethan sleeps in Judy's bed every night while she sleeps in the bedroom recliner. Often Judy's son Danny joins his mother and nephew in their nightly prayers.

May

Judy has her monthly visit with Elizabeth Paulk, MD, a palliative care physician at Parkland Memorial Hospital. She was referred to Paulk after attempting a clinical trial that offered a combination of chemotherapy and radiation that left her too ill to get out of bed. Driven by her desire to remain part of the family as long as possible, Judy stopped the trial and decided to let the cancer take its course, telling her family she wanted to die at home. Palliative care, recognized as a medical subspecialty by the American Board of Medical Specialties in 2006, addresses symptom management and quality of life.

With no insurance and not yet eligible for Medicare, Judy was seen at the county

hospital at no cost, paying a \$20 co-pay for prescriptions.

As with all Judy's visits to the clinic, today is about juggling her medications for pain, diabetes, and high blood pressure. In addition, Paulk must determine the correct dosage of steroids to control the inflammation caused by the cancer in Judy's lungs. The inflammation makes breathing difficult, and the steroids cause stomach ulcers, meaning Judy must stop them periodically to let her stomach heal. Without the steroids, she can't breathe; it remains a tricky balance.

Judy's pain management also presents challenges. Morphine makes her sick, so Paulk must use other drugs. Despite the fact that Judy's pain has increased, she reiterates that she doesn't want to be too drugged to take part in family life.

She fears the time when others will have to take care of her. "The main thing is not to ever become a real burden to my family."

Paulk hugs both Judy and her son, Paul, who has brought her today, before pulling up a chair. She leans forward so she and Judy talk eye to eye as they begin negotiating. Paulk remains softly persistent until Judy agrees to a new combination of patch and pills that should give her pain relief and still allow her to function.

Judy adores Paulk, saying Paulk was the one who gave her some control over how her life would end. Judy also likes Paulk's no-nonsense attitude, adding that Paulk has never pulled punches since they began meeting monthly in December 2005.

Paulk recalls her first discussion with Judy was to reassure her that she wouldn't be letting everyone down if she didn't continue the trial. After relieving Judy's guilt, Paulk began the discussions that would help Judy and the family begin navigating the difficult territory ahead, including how to fulfill Judy's wish to die at home.

Paulk works with local hospice providers, who gradually assume care of patients as they become too ill for hospital visits. Judy has already begun the transition to hospice, with Paulk available for consultation.

Judy says Christy was concerned about calling in hospice at first because she thought they would stop all medications.

"But they don't do that," Judy explains. "This is called 'in care,' and the nurse comes every week, and then I see Dr. Paulk every month."

Judy's registered nurse with VITAS, the hospice provider Paulk engaged during Judy's earlier bout with pneumonia, has just resigned to take care of her own aging father. Judy is now being seen by a licensed vocational nurse (LVN) until another RN is found.

June

The death of any family member comes with the complications of family dynamics. To understand her death and the role cancer has played, Judy wants us

to know about her life.

Heather calls her grandmother “the great Kahuna.”

“Nana can get anybody to do anything she wants,” Heather says. “She is just—she is the head of the house; that’s what she is.”

Christy and Heather are very much like Judy. All three women are verbal, independent, strong, smart, and stubborn. Christy has a full-time job as a top sales manager for a Dallas company. Heather, the first in the family to pursue a college degree, plans to work as a journalist when she graduates.



Judy celebrates her 65th birthday in July with her daughter Christy (center) and her granddaughter Heather (right).

The three women are also aware that cancer plays a major role in their lives. Lung cancer is Judy’s third bout with cancer. She was diagnosed with ovarian cancer shortly after Christy’s birth and then breast cancer when Christy was a toddler. Christy was diagnosed twice with cervical cancer and underwent a complete hysterectomy in 2007.

Christy and Heather are the only nonsmoking adults in the family. “It makes me crazy,” but you can only say so much, says Christy. Food and cooking have always played an important role in the family. Judy still cooks dinner most nights, which provides her a sense of being needed and a role she relishes.

“She is just amazing,” Christy says of her mother, whom she calls her best friend. She tears up when she considers the future. “I don’t know what I am going to do without her.”



Judy (center) gives Christy (left) a lesson in how to remove her birthday cake from the pan while Judy's grandson Garrett looks on.

Judy is effusive when talking about her sons, Paul and Danny, who are the “best sons” a mother could ask for. Indeed, a simple query about what her sons were like growing up finds Judy reciting sports scores and detailing exciting moments in specific games.

But, like other families, the Abernathys have had their share of challenges to bring them to this point.

Judy and her former husband, Richard, were high school sweethearts. Richard, who Judy says is the only man she has ever loved, met Judy when he was 15 and she was 13. They were married five years later, and divorced in 1991. It was a confusing time, Judy explains. She was 46; the family, always the center of her life, no longer needed her, and her husband was building a future with another woman.

During those years Judy studied cosmetology and worked in the cosmetics department of a local drug store. Danny, in his early 20s at the time and still living at home, became her Saturday night date when they went dancing after

selling vegetables at the farmer's market during the day. "We had a good time," Danny recalls.

But Danny was also becoming addicted to drugs and alcohol. Rehab failed more than once. Today, Danny has been sober for almost two years, and the tension of facing his mother's death has made him stronger in his belief that he will make it this time, he says.

Following her parents' divorce, Christy and her mother grew apart. Christy, who divorced Heather's father when she was 3, remarried and began a new family with Glenn Green, an executive with a local newspaper.

A return to church brought Judy new stability and the emotional strength to care for her own mother and sister at the end of their lives. She renewed her relationship with Christy, and when Christy and her husband invited Judy to live with them soon after Ethan's birth, Judy returned to the role where she was most comfortable, that of caretaker. Judy is the hub that brings the family together frequently for functions and holidays that now include her former husband, Richard, and his wife, Dannis.

"[Richard] calls me just about every day," Judy says. "It took me a while to forgive him, but I wanted my children to be around their father, and now it's really good."

Since her diagnosis, Richard and Dannis, who at one time was Judy's best friend, have taken an active role in Judy's life, such as inviting her to their lake home for weekends. (Richard has made all the funeral plans, and Judy will be buried in Richard's family plot.)

Judy feels that she has prepared the family for her death as much as possible, still tearing up when she talks about Ethan and Brandon. Christy agrees that Ethan will have a difficult time with Judy's death as she is the only caretaker he has ever known. Brandon, who is as quiet as Ethan is outgoing, also struggles, she says. Both boys are disarmingly affectionate and loving with their grandmother, someone they clearly adore and protect. When Ethan began showing anxiety about Judy's health when he was 5, she set up an appointment with the hospital's child life therapist.

Judy says it soon became clear that Ethan understood she was dying when he crawled in her lap and cried a "deep, sad cry" before he said he would never forget her.

As Judy's disease has progressed, she has tried to protect Christy from the reality, in part because it allows her to also deny it. Christy says she finally had words with her mother about being honest. "I got really mad at her because she would not let me know how bad she felt and that she was running a fever," Christy says. "We yelled at each other, and it was just an ugly conversation, but it needed to be done. I am her caretaker, and I've got to know what's going on."

As Judy's energy has decreased over the past few months, it's Christy who has been the gatekeeper of her mother's energy and feelings. "It's all about her," Christy says repeatedly.

Judy thanks Ethan for a picture he drew for her.

July

Judy's health is deteriorating. What used to be good days and bad days are now bad days and worse days. The pneumonia is back, and Judy is on antibiotics. The stomach lesions from the steroids are causing excruciating pain, so Judy has stopped taking them, leaving her gasping for breath a good portion of the time.

Judy has begun to talk about dying, and two new malignant nodules have appeared in her neck, sending shooting pain up her arm and shoulder. She has become nostalgic during this month of family celebrations when Heather turns 20, Brandon becomes a teenager, and Danny turns 44. Judy's 65th birthday, on July 19, marks the three-year anniversary of her diagnosis. She has now seen the major family milestones that were important to her at diagnosis: Heather's high school graduation, Ethan starting school, and Danny's success at overcoming alcohol and drug addiction.

On July 12 she celebrated another significant milestone, the birth of her first great-grandchild, Maigon's son, Ryan. She has now held her progeny, and there seems to be a letting go, an assurance that the family will continue.

Now painfully aware of Judy's efforts to say goodbye, a pall has settled over the family, with the exception of Ethan. Too young to understand the dynamics, he is a permanent fixture on or near Judy, playing with toys, watching television while leaning against her chair, or curled in her lap.

The LVN, who has been seeing Judy, has told the children separately that Judy is actively dying. But there is no communication with the family as a whole on Judy's status, leaving everyone confused, including Judy, about her condition.

Christy has always supported her mother's decision to die at home but is frightened, not knowing what to expect when she climbs the stairs to her room every morning. Still, she says, she wouldn't have it any other way.

August

The new registered nurse from hospice has arrived and taken charge, resuming the steroids, which make Judy feel much better.

Terri Branch, RN, immediately informs everyone that Judy is not actively dying as she is still mobile, mentally alert, and her vital signs are strong. Branch, a former ER nurse, soon calms the family with her take-charge approach. Branch begins the process of talking openly with Judy about where she is physically, emotionally, and spiritually.

Judy feels that Christy has been avoiding talking to her about what is happening because she doesn't want to deal with it. "She told me she had to be strong, and I told her she didn't," Judy says. "I said, 'If you need to fall apart and cry, then that

is what you need to do.’ ”



Judy's ex-husband Richard comforts his granddaughters Maigon (left) and Heather after meeting with the hospice nurse concerning Judy's condition.

With her latest bout of breathing difficulty, Judy has begun worrying about Danny. She senses he is depressed. He broke his foot and is in pain. He can't take medication for either issue because of his history with self-medication. She and Richard have been talking more about the children lately, and Richard has promised to take Danny home with him until he is well. Paul calls twice a day, and both sons are ready to be there if needed.

“I have tried to stay on top of everything because when you go to sleep you don't know if you are going to wake up,” Judy says lightly. It's clear she is trying to begin the final discussions she wants to have with her children. “Sometimes you want to say, ‘Hey, I'm dying. Let's talk about it,’ ” she says with a slight laugh. Instead she focuses on teaching Brandon and Ethan to cook, talking them through recipes as they prepare dinner and lavishing praise on their finished spaghetti as only a grandmother can do.

September

Judy continues to decline steadily. The downstairs office has been turned into Judy's sick room with a hospital bed, and she is spending more time there. She has few fully functional days.

Judy's emotional state has deteriorated, in part because Ethan has started to pull away. He has begun spending nights in his own room, which has clearly distressed Judy. She bought him a pair of parakeets to entice him back emotionally, angering Christy. There have been tears on both sides, and Christy encourages her to take the medication the doctor prescribed for depression. Again, Judy refuses.

“I took one of those depression pills a number of years ago,” Judy says. “I didn't like the way it made me feel.” Judy frequently changes her medication to self-manage her symptoms and pain. She is now on oxygen a good portion of the time. “Dr. Paulk told Christy that I was not depressed—I was grieving,” Judy says. “She explained that this will pass, but there are just certain things that set off tears. You don't know it's going to happen, but that's OK.”

Judy says Ethan in particular can't stand to see her cry, saying it will make him cry, too. “But tears are good,” Judy explains.

Ethan, unaware of the pain he is causing, distances himself somewhat from Judy emotionally. Judy says it's hard, but he needs his freedom. For her, he is still her “little man,” who offers kisses and hugs when Judy asks.

Week of October 6

Judy has declined dramatically. She gets up to use the bathroom and to walk outside and smoke, although frequency is steadily decreasing. Ultimately, smoking on the back patio will be her last independent act.

Branch is visiting more often, communicating about Judy's condition every day. Now on a morphine pump, which she can tolerate, Judy's pain is finally managed. Christy, who has taken leave from work, goes in every 15 minutes to be sure she has hit the button. Branch moves Judy to crisis care, meaning an LVN is in the room with her 24 hours a day.



Heather spends a quiet moment with her Nana.

As Judy slips into and out of consciousness, Branch begins to prepare the family for what will happen physically as Judy dies, explaining she will become less aware of the world around her.

But Judy has yet to give up control and has made a number of requests, one of which shows her sense of humor has returned. She asks Christy to be sure they don't "whore her up" at the funeral home with too much makeup.

While Christy has now accepted that her mother is dying and talks easily with Judy, both Paul and Danny feel she will rally like she did in the spring. Each sibling is moving toward resolution at his or her own pace.

On Saturday, Judy says goodbye to cousins, aunts, and uncles who come by the house. The only one who doesn't make it is Judy's brother, who is too ill to travel.



Only days before she dies, Judy manages a smile for great-grandson Ryan and his mother Maigon.

"The boys both went in to see her and said goodbye," Christy says. "Then they walked out and fell apart."

Week of October 13

Branch knows Judy is ready to die, and she is trying to prepare the family for the body's involuntary spasms as organs shut down. Judy is in and out of consciousness and now has a catheter.

Branch arrives on Monday to find Judy in pain and somewhat agitated. "Continuity of care has been a problem for Judy," Branch says. "Other nurses come in over the weekend. I got her pain under control, but it's not good now."

Branch quickly gets Judy comfortable with medication to relieve the agitation.

On Tuesday, Judy gives Christy a detailed list of gifts she wants to buy for the grandchildren with her Social Security check. Both Branch and Christy sense this will be her final act. Judy confirms this by telling them both that when this is

done, she will be ready to die.

Christy buys the gifts and writes the cards for Judy, who doesn't have the strength. When she goes in to sit with her mother, Judy says, "I am at the bar; sit down and have a drink with me."

Christy starts laughing. "She is going back in time. She said to be sure all the guns are set up so the babies can't get to them."

When Judy woke on Wednesday morning she asked to see Ethan and Brandon, so Heather brought them home from school and they spent time with Judy, kissing her goodbye. It was a time of acceptance for the children, Christy says. And each handles it differently. Later in the day, it appears Judy has lost consciousness and there is a sense she has begun her transition. But moments later Ethan gets hurt while he and Brandon play in the back yard, just close enough that Judy can hear the commotion. Judy wakes and, clearly agitated, asks to see both boys to know they are all right. Christy comforts her, but not until Judy has spoken to each boy is she reassured that they are fine.

Branch says this moment is the final rally she expected—when someone who is dying wakes to complete a final task. "She is not afraid to die. She just doesn't want to leave the boys," Christy says.

Branch and Christy notice Judy's left side no longer functions and assume she has had a stroke. She goes in and out of consciousness, and Christy senses she is at peace.

"I went in and she was talking and I thought she was talking to me," Christy says. "I told her I was going to the store and she said, 'I know. I will see you soon, and I can't wait to see you. I love you, Mom. I love you, Dad.' "

As Christy realized that her mother was talking to her own parents, she reassured her that they were waiting for her. "I told her they were waiting to throw her a big party when she got there," Christy says. "She just laughed and got a big smile on her face." The same afternoon, Heather visited her grandmother, leaning over her unconscious form to whisper, "I love you, Nana." When she did, Judy opened her eyes and very clearly said, "Why are you crying, baby?"

Friday, October 17

The boys want to stay home from school, and Christy agrees, sensing they are exhausted, as is the whole family. All Judy's children and her grandchildren, along with Richard and Dannis, hold vigil at the house. The family cooks, talks with each other, and goes in to sit with Judy—despite her inability to respond. The tension is gone, and goodbyes have been said. Family members hug each other when they pass and sit entwined on the couch as they wait.

Christy senses her mother needs the quiet of the home she has lived in for the past seven years, knowing that Judy's will to live keeps her responding. The need to hear her voice one last time makes it hard for those she loves to not try to wake her. They all agree to leave. Richard takes Danny home, and Paul and his

family also leave. The house is quiet.

Christy sits with her mother that Friday afternoon, holding her hand. She watches Judy's lips move in conversation. "She is talking to someone who is coming for her," Christy says.

In the early hours of Saturday morning, Judy dies the way she lived—on her own terms. Her pain finally under control and having said all her goodbyes to those she loved, Judy met those who were coming for her from the house where she had raised a second generation of Abernathy children.

In a final discussion while she was still coherent, Judy offered advice for the living.

"People need to tell the people they love how important they are and how much they love them," she says. "Don't wait; tell them now because it's the only thing there is."

When the LVN realized Judy had died, she woke Christy, who sat alone with her mother before calling Branch. Upon arriving, Branch took care of the technical aspects of the home death, and then called the funeral home.

On a beautiful fall day, Judy was buried in the Abernathy family plot in a small Texas town north of Dallas where she now lies in death as she lived her life, surrounded by family. In the casket, Christy fulfilled her mother's final wish that she be buried with a copy of her favorite movie, *Lonesome Dove*.



The family comforts each other at the end of Judy's funeral. From left: Paul; Richard hugging his stepson; Christy and Ethan hugging Garrett; Heather; Christy's husband Glenn; and Brandon (behind his father). Judy was buried in Richard's family plot in a small North Texas town.

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Judy's death has left an unimaginable hole in the family, and Christy says they are all still grieving. In looking back, she says there are no regrets about the way the family handled Judy's death with the exception that she wishes she had been able to talk to her sooner about dying.

The Sunday before Christmas some of the family visited the cemetery, and Christy says she sat at her mother's grave and talked to her for more than an hour.

"Not that I don't talk to her every day," Christy says, "but it made me feel better. I think Mom went with peace of mind. I think her only regret was not seeing her brother. It was the only thing we couldn't give her."

Christy says each of the children and grandchildren is grieving in his or her own way. Ethan initially refused to go to the funeral but then agreed to go. He refuses to sleep upstairs and spends nights on the couch in the den. Brandon calls Heather to talk, and on more than one occasion has begun crying when he and

Christy are alone. Paul agrees that there is the sense that Judy will still be there for holidays and special events. Danny has remained sober and is doing well.

The weekend before Thanksgiving the family gathered at Richard and Dannis' home. It was very hard, Christy says, since Judy's absence was clear. Mostly the family talked about her and cried.

A place Judy has been sorely missed is in the kitchen. Christy says she has had to call Paul for family recipes and he has begun putting together a cookbook of Judy's favorites for the family.

Christy says it's Brandon who usually steps in to help. "I made cornbread last week, and Mom always put cayenne pepper in hers. We took one bite and Brandon looked at me. I said, 'I forgot the pepper.' "

Christmas was particularly difficult because it was Judy's favorite holiday, and she had started traditions for each of the children and grandchildren.

"Mother bought the boys new ornaments every year at Christmas," Christy says, "so I did that this year."

Christy delayed putting out the decorations until the last minute, unable to muster the spirit her mother loved so much.

When she took out the box of snowmen that her mother had collected for her, Christy opened the box to find a note.

"She sensed last year that it was her last," Christy says. "She put the note in when she put up the decorations. In it she reminded me of how much she loved Christmas and asked me to put out all the decorations with the same love that she did."