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## A Gentle Death: Five Months with Hospice

### By Barbara O'Neil Ross

Following the death of her husband, John H. Ross, in December 2002, Barbara O'Neil Ross began writing about their experience. John spent over five months in the care of Hospice of Cambridge in MA. Both John and Barbara were strong believers in the benefits of hospice care, becoming familiar with hospice through reading and the work and efforts of good friends. After the death of Barbara's mother in 1983, which Barbara felt was prolonged unnecessarily causing her mother additional suffering, her support for hospice intensified. She and her husband both knew that they wanted to give John 'a gentle death.' Barbara's nine-part series, *A Gentle Death: Five Months with Hospice*, captures the essence of hospice care and the various roles the hospice team can play in the lives of the dying and their loved ones.

Barbara O'Neil Ross has a B.A. in Psychology from Stanford University, and a teaching degree from the University of California in Berkeley. She taught language arts and math in Colorado, San Francisco, and Manhattan before marrying and moving to Cambridge, MA. In her 30's she did the illustrations and some writing for two cookbooks published by Doubleday. Since then she has focussed on art projects, including several environmental pastel series, and has taken several writing courses. Currently, Barbara is a professional artist living in Palo Alto, CA. She is an avid supporter of hospice.

Except for her own name and that of her husband, Barbara has changed the names of all the characters in her stories for privacy reasons.  
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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 1: Our first week with hospice

"You know this is the beginning of the end," John's lung specialist tells me over the phone when I ask if he will authorize hospice care. He agrees to sign the required papers predicting a life expectancy of less than six months - but seems reluctant.

Awake most of the night, I agonize over the decision.

Next morning I phone the primary care physician, an old friend of my husband. His response to hospice - "I'm so relieved to hear this. I was afraid you didn't realize how serious his condition is."

A few days later a starchy Scottish woman arrives with a mountain of forms. She pulls her chair up to John's bed, her kind eyes looking directly into his, and says, "You know, love, your lung disease isn't going to improve." Her warmth and honesty put us at ease.

Two days later the hospice team hurtles into action. Peter, the furniture mover, puffs up our stairs carting a hospital bed, furniture is rearranged. A bed-table, shower chair, wheelchair, and commode appear. Caroline, an energetic blond brown-eyed nurse, makes her first call and instructs me in the use of morphine - "You fill the dropper to just this number of milligrams - just to this line - no more. Here's a box of medications that needs to be refrigerated." Tom from the oxygen company places a huge can in the downstairs bathroom and shows me how to set the meter, refill the water bottle, and check to see that the tubing is clean. The tube is long enough to go up to the bedroom, tangling on the newel post and tripping up the cat.

Next day Rosa, a smiling round Haitian woman and nurse's aide, appears at the door ready to help John take a shower. She will come every Monday, Wednesday and Friday.

John, a calm New England craftsman and gentleman, seems remarkably able to take all this in his stride. I am falling apart. A hospice social worker calls to say she'd like to meet us before she goes on vacation the next day. She's at the door at about my nap time. John is sleeping upstairs. Bleary, I try to answer her list of questions, "How long has your husband been ill? I'm sorry to ask, but have you selected a mortuary? What are your husband's interests and activities?"

"He's planning to dictate some family stories to a friend," I say.

"Oh, he likes to write? Perhaps do an autobiography? Well I can get him a book called About Me that might help him get started. It asks leading questions like, 'What is your favorite color?'"

My husband majored in English, is known for his unique way with words, and has a delightful style all his own. I can't wait to get this well-intentioned woman out of the house. I close the door behind her and giggle all the way to my bed. Wait until I share

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this with John.

“WHAT IS YOUR FAVORITE COLOR??”

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By Barbara O'Neil Ross

### Part 2: Joan

Next morning I phone the hospice volunteer office: "I'm so sorry to tell you this but the social worker who came to visit yesterday just doesn't seem like the right person for us. Are there other possibilities?"

"Oh yes, please don't worry, there are other choices. Someone I think you might like is our Chaplain, Joan Weber. She's a lovely person. Should I have her call you?"

A few days later there's a ring at the door. On the other side is a middle-aged woman in a mauve wool jacket. She has a soft southern accent and a kind approachable face. I feel a rush of relief. I lead her into the living room and introduce her to my husband. John is wrapped in his flannel plaid bathrobe leaning back in his favorite dark blue reading chair.

Joan tactfully inquires about our religious preferences. "We are spiritual but not in a conventional ritualistic way." Wisely she does not push the subject. Later we will talk about memorial service plans, but right now she seems to be here to learn about John and to affirm the value of his life.

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[Barbara O'Neil Ross and John H. Ross, 1967]

Over the weeks Joan comes and talks to John about his family and childhood memories. He describes the time he was in the woods with his father trying to chop wood. A slip of the axe sends the blade into John's knee. "Pa" he calls out, "I think a

Band-Aid might be needed.” At the hospital John's knee is decorated with more than a dozen stitches.

She hears about his high school football days, and the embarrassment of having his petite mother running back and forth along the sidelines calling out, “Gentle, Johnny, Gentle!”

John tells Joan about our life in a remote part of Colorado where we made furniture and a terrace out of available Aspen trees and red rock and waited in the dark of evening for deer and beaver to appear.

She asks him about his teaching. “How many years have you been a teacher?”  
“Oh, about 40 years.”

“And how many students a year?” “Let’s see.....probably 200.” “That would make about 8,000 young people you have influenced over your lifetime. John, you are a born teacher. You have such a calm acceptance of your illness and such a generous spirit and positive outlook. You are still teaching. You are teaching people how to die.”

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 3: Charlotte

Two weeks after we start with hospice, I am given the chance to pick among several volunteers described to me. Charlotte sounds like a fine choice, a down-to-earth retired therapist with a devoted following.

The minute I see her I know this is going to be someone who will play a significant role in our lives. She's an empathetic and pragmatic New Englander - straight short hair, kind eyes and a sense of humor. She's quick to see what's needed. She finds a book stand so that John doesn't have to hold up the hefty nautical tale he's currently reading. He's having an eye problem and needs a patch. I've sewn a crude black one. Charlotte creates one that fits perfectly over his glasses and stitches a "J" on it in contrasting white thread. She knows how to convert a pullover sweater into a cardigan with zipper.

Charlotte brings her handwork and sits peacefully with John while I do errands. She's here when the Pacheo Brothers come with three tables John has recently worked on. They are helping John finish the job. Charlotte helps me get him into a comfortable position to carve his initials in the mahogany. She encourages me to join the Mt. Auburn Club and use the pool there. She is a steady calming presence. We need her. While preparing John's breakfast I find myself dropping the egg in the disposal and putting the shell in the mixing bowl.

When John and I watch TV in the evening, I sit in a reclining slate blue chair by his bed. I hold his hand with my right hand; my left hand is on the rump of our beloved cat, Pawla. She rests her chin on my knees. Sometimes I weep silently. I feel these two are all I need to be content. Charlotte would understand.

"When the time comes, you will find that you have the strength."

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 4: Rum and Therapy

"Barbara, you don't have control over the timing of John's death."

These are the wise words of a therapist I'd contacted when I knew I was going to need help dealing with my sadness, anger and stress during John's illness. Part of the frustration and the pleasure of being a caregiver is trying to anticipate the patient's every need and the feeling that if you just do everything right, this person you love will be more comfortable and will live longer. It is exhausting.

"Once a month I want you to treat yourself to a little holiday from nursing. Spend one night away from home and do something fun."

Within days I am behind the wheel of my VW Golf heading for the Arabian Horse Inn in Sudbury, a charming spot with giant old oak and ash trees dotting a vast hillside. I wander over to the duck pond and stand by the fence watching two gray Arabian horses flicking flies off each other's haunches.

Back in the spacious bathroom, I spill an overdose of bubble bath into a huge square maroon tub and luxuriate in the suds and froth as bubbles flow over the tub rim.

Later, lying on my back on the grassy slope, looking up at the shifting cloud patterns, I listen to the purr of Tiffany, the farm mouser, who parks her chubby white and black body on my stomach. Her desire for affection is insatiable. Every exposed square inch of my dark knit clothes is covered with white hairs. I feel at peace.

The next little vacation is at a B & B in Cambridge. An essay for an upcoming reunion, "My Journey Since College", is overdue. After mint tea and chocolate cookies, I tackle the task. Propped up against pillows in my lacy canopied bed, I try to stitch together the varied threads of my life. It takes most of the day and evening but is unexpectedly therapeutic. I can see how my current situation fits into the total fabric of my life.

A month later I crumple into another B & B . After a nap, I explore the neighborhood, pretending to be a tourist, discovering amusing little stores, buying a few cards. I watch TV and read, uninterrupted. Next morning I feast on an enormous artery-clogging breakfast - an omelet, sausages, muffins. Very satisfying, but I know I'm not completely refreshed when I stop in at an unfamiliar liquor store on the way home.

"Do you happen to have any Ben Gay Rum?" I inquire.

He grins. "Lady, do you mean Mount Gay Rum?" I burst into laughter.

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By Barbara O'Neil Ross

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### Part 5: Caroline

A car door closes and I hear someone bounding up our front steps. It's Caroline, the vivacious blonde hospice nurse who comes at 9 a.m. every Tuesday and Friday. It is a pleasure to open the door and hug this spirited brown-eyed young woman. She is the epitome of crispness, with her rapid speech and extensive wardrobe - vivid colors, just-ironed blouses and skirts cinched in at her small waist with assorted belts.

Caroline sprints up the stairs to John's bedside. "Hi, John, how are you?"  
"The better for seeing you, m'dear."

Before long I can hear the clapping sound of Caroline's cupped hands striking John's back. It is respiratory percussion treatment that she has willingly learned from Nina, our pulmonary therapist. Simultaneously, I can overhear a brisk conversation. Caroline tells John about her belly-dancing class and bicycle trips. He intrigues her with his past ventures: circumnavigating Baffin Island in a Russian freighter, mountain climbing in British Columbia, his acquisition of a schooner in Seattle. Between coughs I hear laughter.

After several months of these visits, Caroline arrives one day with a sizable brown medicine bottle. The prescription label is marked, "A dose of humor. Take 4X a day. Dr. Chuckle." John opens it up. Inside are slips of paper; on each one a silly joke.

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 6: Caroline (again)

By December, with the help of oxygen and his support team, John is still able to enjoy many activities. One Saturday he is feeling droopier than usual and seems to have cold symptoms. By Sunday afternoon Nina and Caroline diagnose pneumonia. His lungs are very fragile, his oxygen level dangerously low; we all know this is a critical development. John is too weak for lung therapy, so Nina reads to him from his current choice of books: Into Thin Air.

Caroline and I have a tearful conference in the kitchen. She could prescribe antibiotics, but tells me that if he survives pneumonia, his life will be severely compromised. He will probably be bedridden. I know John's feelings about this issue; we have talked about it many times. We decide to keep him comfortable with morphine.

It's a challenge to find additional help on a Sunday evening, but Caroline is tenacious. After many calls she reaches a trusted Polish nurse who will stay with John overnight. As Caroline departs, John asks, "Would you mind hiking back up the stairs so I can see your new red coat?"

She returns early the next morning. John is slipping rapidly and Caroline dashes back and forth to her car getting equipment. She calls in another aide to be here when she has to be out briefly.

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[John H. Ross, 1925-2002]

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By afternoon John is in a coma. Caroline tells me and John's devoted sister and niece, who have joined us, that the last sense to go is hearing. We can each say goodbye to him, and he will receive our messages. She suggests we try to reach his children. Miraculously, both Ellie and Craig, who live active West Coast lives, answer their phones. We hold the phone up close to John's ear.

Each of us in turn makes our final comments to this original, much-loved and courageous man. I ask to be alone with him.

Caroline's final words express what all of us feel: "John, it has been wonderful to know you and to be able to be part of your life. You are the perfect gentleman."

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 7: Mending

The year before John died I visited a psychic in California. I've had sessions with Vivian before. She is a warm-hearted, jovial, sensitive woman whom I have learned to trust. Her insights amaze me. I told her I'm not good at departures and wonder how I can possibly get through the sadness and emotional turmoil of the next phase of my life.

"When the time comes, you will find that you have the strength."

.....

It is nine months after my visit with Vivian. The minister, David White, and I are putting the finishing touches on the memorial service. I've had six weeks to plan it since John's death. Incorporating John's suggestions, I have encouraged some of his close friends and family to write briefly of their memories. David and Joan will read these remarks. John's sister and children and two friends will speak about him. We have gone back and forth on e-mail honing these comments and reducing duplications. Organizing the service is a healing creative process, a way to distract me from the silence and the sorrow. I love reading what people remember about John and the tenderness and humor they express.

February 1st finally arrives - a raw white day. My beloved sisters and their families have arrived, and we are waiting in a side room at Christ Church. The church is crammed and I can hear the strains of "How Lovely is Thy Dwelling Place." I know this is going to be a deeply satisfying tribute to my lovable quirky husband. I find a strange calm sweeps over me, and I think of Vivian's assurances. I have a great sense of anticipation. It's as if I have produced a play and look forward to the audience's response.

Sitting in the front row between my stepdaughter and sister-in-law, I am deeply involved in the words being spoken, and find I can actually sing the Navy Hymn without crying. Part of me feels as though I am watching from above. I am looking forward to the moment when the minister reads the story of "Old Fluff." I have written up this family legend and know it will be warmly received, adding a moment of comic relief. At last it comes, and David reads it with just the right straight-faced expression:

*John had a favorite old sweater, a tawny-colored wool cardigan, that he called "Old Fluff." Holes, particularly in the elbows and wrist areas, had been patched and mended many times over the years. It was in a very frayed state when it was suggested one day that it might be time to retire this garment - NOT a welcome thought. About then John discovered in The New Yorker an ad for a Sweater Hospital in Maine. So he carefully bundled up the sweater and sent it north with a letter that said, "Enclosed you will find 'Old Fluff' - I hope you can revive her."*

*Within a week a letter arrived:*

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*Dear Mr. Ross:*

*We have received 'Old Fluff', but due to her critical condition, we have had to put her in Intensive Care , which will cost an additional \$8.25. If you would like us to proceed with the operation, please let us know."*

*A few weeks later "Old Fluff" came home, restored, and ready to start a second life.*

The story is accompanied by ripples of hearty affectionate laughter from the congregation. For me it is a short interlude of profound joy.

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 8: California Memorial

"Barb, you can play the tape and have a party here if you'd like to." It's the gentle voice of Sue Randall, my dear friend and college roommate. We've been discussing a way to bring the February memorial service to John's and my West Coast friends. "I'll even let you plaster my dining room walls with the wonderful photos you exhibited in the Church".

It is March and I am in my hotel in San Francisco listening to the recording. The sound is rather faint. Will people be able to hear? I'm feeling nervous about how this will all transpire with no ministerial figure there to officiate. I will have to make some kind of introduction. Public speaking unnerves me.

Sunday arrives. I feel the thrill of seeing so many loving friends mixed with some fear that this event won't be what I've imagined. Sue's living room is arranged with twenty chairs surrounding a coffee table where we place the newly rented high-tech recorder. People have been introduced and have found their seats, and I know it's time for me to act. How I wish John were here to do this - he relished a chance to address a crowd. I feel emotionally vulnerable in this room where we are all facing each other. I'd like to creep into a pew. But I manage to get to the center of the room and welcome people and say a few words before switching on the recorder.

The crowd is so attentive, straining to hear each word. We're just getting to the part where the splendid baritone student who lives with us will sing "Jerusalem," when Sue's neighbor slams out of the house next door loudly whistling "It Had to be You." There is a flicker of amusement around the room.

I have handed out the program from the original service with the music printed in it. When it's time for the "Navy Hymn," twenty brave souls stand and try to sing along with the tape. It is painfully off-key but a noble effort. Part way through, Sue's daughter's parakeet, who is caged nearby in the kitchen, joins in with a piercing vocal accompaniment that nearly drowns out our quavering voices.

We're mid-way into the recording now and David, the minister, is reading some of the poignant tributes to John. I begin to hear a strange noise. It sounds like deep breathing. No, I think it's actually snoring. Unobtrusively I begin to study each person in the circle, trying to determine the source of this distracting rhythmic rumble. I watch chests rise and fall. If it's someone snoring, why doesn't his neighbor provide a nudging elbow? The sun is streaming in the window toward me making it hard to read the backlit faces of people sitting across the room. I squint. It couldn't be that handsome woodworker sitting on the couch or the alert woman next to him, yet that seems to be the direction of the sound. It might be John's decrepit lawyer friend, but I think his eyes are open. The volume of the noise increases. We're getting to the end of the service and people are exchanging puzzled looks. The trumpets blast off the ending, "When the Saints Go Marching In." Our crowd creaks to its feet.

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Out from deep under the table at the far side of the couch lumbers the Randalls' ancient and still drowsy black Labrador Retriever.



*[Barbara O'Neil Ross and John H. Ross]*

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## A Gentle Death: Five Months with Hospice

By Barbara O'Neil Ross

### Part 9: Charlotte (again)

After John dies Charlotte comes on a weekly basis for over a year to help me sort through John's belongings or just sip ginger tea and talk. Together we go through closets and drawers, tossing shirts in grocery bags to go to The American Friends Service, placing patched clothes into boxes to put on the street, stuffing stained items into trash bags. John's oldest shirts are nearly filigree; he liked them when they were worn sheer. When he returned from a sailing cruise you could see where the sunburn ended at the double fabric in the shoulder area.

We go through his desk and files. There is a set of keys with a note attached in John's unique scrawl - "Grandpa's tool chest?". There are little metal boxes with rubber bands, screws and Yugoslavian coins, and an appalling number of hole punchers. There are rocks from the Antarctic and bones from Newfoundland. Some correspondence dates back to the 1930's. John was a recycling fanatic. When we occasionally toss a piece of paper in general trash we raise our eyes skyward - "Sorry, John." I sort, and giggle, and mourn.

It is October, almost a year since John's death, and Pawla's health is failing rapidly. I am frantic trying to find food she will eat. Charlotte is with me and gently suggests it might be time to put Pawla to sleep. For days I am weepy, but finally make the call to Dr. Branson. Charlotte drives to the vet, trying to soothe her inconsolable passengers. Pawla's body looks so flat lying on the metal table during the injection. I sob when her body goes limp in my arms. For sixteen years I have loved this animal. Dr. Branson has tears in her eyes when she gives me a little piece of fur to take home. The ashes will follow.

Two and a half months later after checking out various declawed domestic shorthaired cats on the Internet and just missing out on a tuxedo described as a "feline counterpart to Cary Grant", I decide to stop the search temporarily until after the family Christmas visit. But an obsessive part of me can't resist checking on Petfinder.com.. Suddenly an adorable face appears on the screen - a four year old tabby at the Brockton M.S.P.C.A. I show it to Charlotte - "Let's drive down there and look at her." So I grab the old cardboard cat carrier, put out the litter box, and we hop into Charlotte's car and head south.

At the pound they put us in a cubicle and bring in a handsome shy beast who immediately hides behind the computer, looking out with frightened chartreuse eyes. As we sit there, she ventures out to sniff us. She's a beauty with a stunning black Rorschach pattern on her back; white paws, chest and tail tip. The attendant takes her off for a distemper shot and tells us that "Jewel" purred throughout the procedure. That does it. Next thing I know we're on our way home with a full, meowing box in the back seat. We settle this new mound of sweetness, renamed "Truffle", into a small downstairs room. I am sitting on the floor stroking the velvet ears of my furry new companion when Charlotte slips out the front door.

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