

**COLUMN ONE; Lessons in the Art of Dying--and Living; Talking of love, regrets, dreams and hard choices, 'students' in classes led by a former priest confront a reality often denied in our culture. Their goal; to craft a better death.**

*The Los Angeles Times*; Los Angeles, Calif.; Dec 21, 1997; MARIA L. La GANGA;

**Abstract:**

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*Through five weeks of talk--interspersed with five weeks of lecture and talk--we learn how to fill out documents that allow us to die without the aid of machines. We discover how our bodies will react, one week, one day, one hour before the end. We argue about the very best way to go; renal failure wins hands down, with its dreamy drift from unconsciousness to death.*

*This is a real conversation-stopper at most polite dinner parties, and that is precisely the point. There are very few places to say things like What happens to my body on my last day? How can I make sure it doesn't hurt at the end? I'm lonely. I'm dying. Maybe I'm not dying. But I'm afraid.*

**Full Text:**

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This is Paul's dream of the perfect death: Retired math teacher, avid sailor, he circumnavigates the globe at age 99, is lost at sea and never seen again. His hands shake a little with Parkinson's disease as he tells this story in his soft, wheezy voice. Dapper in plaid shirt and neat jeans, Paul sounds as if he is talking about someone else. Lost at sea. Never seen again. Almost as if he will not be there when it happens. Lost at sea.

He repeats this story often in the neat apartment off Golden Gate Park where we meet for 10 successive Monday nights, September to November. Autumn deepens all around us. Leaves fall. Days shorten. We are here learning how to die.

We are not boning up on how to kill ourselves, although the topic does arise on occasion. Legislatures and courtrooms, talk shows and pundits may fixate on assisted dying, but it is somehow almost beside the point to the women and men who gather here hoping to craft a better death.

Pain is a far more important topic when we peer closely at the end of life. God, too. Love, regrets, family, paperwork, morphine. We have much to discuss and not much time--20 hours in Richard Wagner's living room.

Through five weeks of talk--interspersed with five weeks of lecture and talk--we learn how to fill out documents that allow us to die without the aid of machines. We discover how our bodies will react, one week, one day, one hour before the end. We argue about the very best way to go; renal failure wins hands down, with its dreamy drift from unconsciousness to death.

As traffic whizzes by outside, drowning out the occasional quiet confidence, we face each other in an intimate circle. We talk.

A lot happens from September to November. Paul and Sophia, both 80, sell off some property, celebrate 55 years of marriage and 55 years in this adopted city. Yet another friend dies, No. 6 in the last year or so. They give most of their belongings to their children, apply for rooms in a home for seniors, argue about whether or not to go.

Famous architect Julia Morgan built the place. It is red brick and graceful. Close to the marina, Sophia says one day when Paul--again--brings up his final voyage. Paul does not want to move, not into this place, this hotel, this antithesis of home and comfort.

Adina travels further along in the process she refers to as "active dying." She is 43, has cystic fibrosis. Her oxygen tank soughs in the background. She coughs a lot. When we first meet, she is in danger of breaking her First Commandment: I will die with the lungs God gave me. She is freshly back from a trip to Stanford University Medical Center, an exploratory jaunt in search of a transplant.

By November, she is cleared for surgery, on the list and debating what to do. She wears (and forgets) and wears (and forgets) the beeper that links her with the medical center and the organs that could come at any time--or not in time. She

looks at her prescriptions and credit cards; she will likely expire before they do. She laughs. Sometimes.

By the end of our discussions, Sandy will make love for the first time in a very, very long time. Well coiffed, perfectly made up, unable to stop smiling as she makes her announcement--Yes, I did it--she has come a long way.

In September she was shy, maybe just a little dowdy, part way through radiation treatments, done with chemotherapy, at war with a body that betrayed her with breast cancer. A body that she was never all that comfortable in to begin with.

And once they start cutting around in your parts, she says, and her voice trails off. She cannot finish this sentence. Not in September. In September, she says, I need to learn how to live as much as I need to learn how to die.

Which is precisely the point of this exclusive club. We are not just people who are going to die; if that were the case, you would all belong too. The eight women and three men know we are going to die. This is a big difference.

I am here in part to listen, but also to learn. I am healthy but an actuarial nightmare: practically the only member of my family not to have had cancer. At 38 years old, I am without a female relative who made it to 50. My mother died fast in 1973, one quick yank of a ventilator plug after rapid brain cancer and ineffective surgery. My father died slowly two years ago, as his body parts fell to age, disease, a lifetime of smoking. They left the ventilator on. He dwindled.

This is a real conversation-stopper at most polite dinner parties, and that is precisely the point. There are very few places to say things like What happens to my body on my last day? How can I make sure it doesn't hurt at the end? I'm lonely. I'm dying. Maybe I'm not dying. But I'm afraid.

This is that place. It is not perfect. It is sometimes hard to bear. In most cities, finding something comparable is impossible. It is not for everyone. But it can be very helpful.

"What is magic about what happens here is that everyone is a self-identified mortal," Wagner says in October. A gay, defrocked Catholic priest who lost most of his friends to AIDS a decade ago, Wagner started this series of classes in 1995 for senior citizens and the terminally ill. At first, it was largely attended by gay men with the AIDS virus. Today, as AIDS treatment improves, it is largely women with cancer.

Wagner earned a PhD in clinical sexology while a practicing priest, but his doctoral research on the sexual attitudes and behavior of gay Catholic clergy knocked him out of favor with his church. While he has spent the last 14 years working with the dying, these days he is a sometime-therapist who pays the bills with a secretarial job.

He calls this group Paradigm: Enhancing Life Before Dying, a grand name for a worthwhile, but shoestring, operation. Lecturers donate their time. Wagner bakes the refreshments himself. Participants are asked to donate \$10 per session if they can.

There is no money to advertise. Sandy heard about Paradigm in chemotherapy. Wagner gave Sophia, white-haired and charming, a brochure on the group as she got off a bus. He does this sometimes with people who look old and open-minded.

Some names have been changed to protect privacy. Wagner's is the only one unaltered. All stories--the heart of a process like this one--are true. "When I'm with you, what happens here, I can't manufacture with my friends," Wagner says. "They have not taken that important leap: 'Yes, I'm a mortal. I'm going to die.' "

## Session I

What is your first remembrance of death?

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This is how we begin our long conversation. For a group that ranges in age from the 20s to 80, whose youths spanned this century from World War I to the end of the Vietnam War, our responses are strangely uniform in tone. They are filled with pets and grandparents, silence and moments of inadvertent dark comedy, like Ellen's Depression-era tale of death and dinner:

"My father lost his job and went to raising chickens in the garage. And we got the chickens when they were little babies, and I named them all, and I loved them all, and then my father would take them and chop off their heads. And they would run around the yard, and I would cry, because I knew which chicken that was. And then I had to eat it."

Sandy's "first death" is more the norm. She is 7 years old, in Joplin, Mo., when her grandmother dies of leukemia. She doesn't see it happen and doesn't hear much about it. "I remember them coming to me and saying, well, your grandmother won't be coming home. People just go away, and they don't come back."

Sandy remembers no funerals as a child, even the ones she attended. Even her father's when she was 16 and he was 39 and a salesman in the family cookie business when he died of a heart attack. Although she didn't realize it then, it changed her life. Yet she cannot even call forth an image of a coffin with her young self nearby.

She has introduced herself on this first night this way: My father died at 39 and I kind of thought I would too, so I didn't really make long-term goals. You don't know it while you're doing it.

All of a sudden she finds herself in her 40s. Stuck, really. Personal adventure seems to have ended. A set painter, she has shifted subtly from artist to craftswoman, from creativity to rote. When a love affair ends, she finds no substitute.

She is thinking that she wants to go visit places one last time. "I wonder, in essence, how much I killed myself off. I always planned on having life be over at that point. So I sort of finished things."

By the time a routine mammogram comes back and she hears the chilling instruction--Find a surgeon--it is five days before Christmas in 1996, and she has outlived her own personal life expectancy by seven years. Four weeks later she is diagnosed with cancer. Twenty days after that, the lump is removed.

She cannot bring herself to ask for help, fights the dependence that comes from serious illness. The lumpectomy means she cannot raise her arm. Chemotherapy makes it hard to drive. She feels guilty, apologizes for her temporary helplessness. It is, she says on our sixth night, a horror--with one small, sweet exception.

Sandy had been estranged from her mother for years, separated by geography and difficult circumstances. Now "I happen to be one of her greatest supporters from the time that she washed my hair. In the process, I remembered being a little girl. You get soap in your eyes and you're fighting and all that. You never dream that you'll be sitting there at 47 years old with your mother washing your hair. And we're laughing about it."

## Session II and III

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The first several Mondays are filled with revelation. Ellen, 71, says she wants to be immortal, plans on being cryogenically frozen in a tank filled with nitrogen for

"reanimation" at some future date, displays the Medic Alert necklace she is never without: Resuscitate-cool. No autopsy.

Adina, getting sicker, cautions calm if by some chance she coughs up blood. It happens sometimes is the nonchalant disclaimer from the petite woman with the oxygen tube that loops from tank to nose.

Paul is stunned by the recent wit's-end cry from the wife of an ailing friend--a man who has Parkinson's disease just like Paul. "It was his wife, a very loving wife, very caring, and she read a statement that said she wished Joe would die," he says. "That was a surprise to me."

Sophia announces her plans for their future with a cheerful "Paul and I are considering going into a retirement community, and one of the things we have to do is plan what to do about our bodies." Later, she is thrilled to find a low-ball bidder--a full-service cremation for just \$395 per person, close by on Valencia Street.

We are learning the vocabulary of the end of life. We are practicing with our newfound voices to speak of longtime fears. We are given a list of 18 awful eventualities and pick our personal worst. We are confronting our fears. The top three: I'm afraid of being helpless and having to depend completely on others. I'm afraid of taking a long time to die. I'm afraid of losing control of my bodily functions.

Carolyn, in her 20s and infected with HIV, is most afraid of losing those she loves. "In thinking about dying, one of the things that makes me want to go on is that I love the people in my life. I'm stubborn. I really want to stick around. I want to have children and grandchildren. I want to have the length of life my parents had. I don't want to give it up before I'm 30." Carolyn has been married for just four months and leaves the group after just three meetings.

#### Session IV

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There is little fear of post-death punishment in this small crowd of Unitarians, lapsed Catholics, lukewarm Methodists, sort-of Jews. But it is telling, as we speak of spirituality and death, that even those among us with a system of belief feel that it may not be enough.

Our search for spirituality seems as much a longing for community as it is for faith, as much for people with whom to celebrate ritual as it is for the ritual itself.

Still, the yearning for spiritual comfort is there. The answers are not. Question: Is it easier to die if you believe in God? Answer: Not necessarily. Who knows. Sometimes. And, sometimes, a resounding no.

David Pettee, hospice nurse, Unitarian minister, our guide through this slippery subject, believes that "thinking about large unanswerable mysteries in our lives as we're facing our mortality, that to me is what spiritual work is. And it tends to be better when done in relationship with other people."

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As the flashier part of the national discourse on death--whether your doctor should help you kill yourself--threads its way into ballot initiatives and headlines, there is surprisingly little controversy or even discussion around the issues central to Paradigm: Is there a right way to die? Can you teach someone how to die? Should you teach someone how to die? If you can, if you should, who in their right mind would want to learn?

Of the hundreds of books on store shelves, of the thousands of Web sites that choke the Internet, of the countless support groups that lend a shoulder, very few are for people actually dying. Unless you reside here, you likely have little access to the small number of struggling organizations that make up the conscious dying movement.

Unless you are in a hospice program or are very, very lucky, your doctor likely views death as failure and does not want to talk about it. Even if you are fortunate enough to receive the ministrations of hospice workers, it may be too late for you to benefit much.

Hospice care, by legal definition, is for the terminally ill with six months or less to live. This is theoretically time enough to put your affairs in order, to reach out to your loved ones, to teach those around you about the kind of death you want--and don't want. But more than 15% of all hospice patients die within a week, because they, their doctors and their families cannot admit sooner that there is no hope.

What is lost by this denial? An opportunity to become more human, says Dr. Brad Stuart, medical director for VNA & Hospice of Northern California. "What I would call the basic spiritual message that dying brings us is that we move toward wholeness, and wholeness doesn't always feel good," he says. "When you become a truly whole human being, you assimilate the lightest parts of being human and also the darkest. . . . People who are dying and their families become more human, and that's what I'd call growth."

Americans, says Dr. Ira Byock, author of "Dying Well: The Prospect for Growth at the End of Life," are perhaps not ready for this discussion, not prepared to embrace an active role in their own deaths. Asking why there are not more services addressed specifically to the dying in 1997 is like asking why there were not more home births in 1966.

"We're five years too early," Byock says. "The generation of baby boomers, a third of this country, is just now dealing with these issues in a way that is forcing them to rethink traditional approaches . . . We're beginning to get there. The problem is that denial can really rob us of this opportunity."

## Session V

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If Americans cannot speak of death, imagine a conversation on sex and death, our biggest taboos twinned together. This is our topic tonight--sexuality, intimacy and death. Half the chairs in Wagner's living room remain empty, perhaps because of a scheduling mix-up, perhaps because of the subject.

It is a night full of loss and longing, of bodies that no longer function the same way, of scars and oxygen tanks and shortness of breath. Of rejection.

Adina's grief is perhaps the most palpable. I actually feel a lot closer to dying, was her somber beginning to our last meeting. Tonight she is feeling better after two weeks on prednisone. The steroid was prescribed to clear up a fungus in her lungs, an ailment that produces more labored breathing and could stand in the way of a lung transplant.

But improvement comes at some cost. Now she has steroid-induced diabetes, which means more medication and constant blood tests. "In some ways it's worth it," says Adina, who is on her second trip through the Paradigm process, this time helping facilitate the group. "It's quality of life. I'm not going to worry about all the horrible things that can happen to you if you're on it for 10 years. I won't be on it for 10 years."

Adina has known from childhood that she would never be blessed with old age. Her friends joke that she's been dying for as long as they've known her, that they've been hearing about this death stuff forever. Two years ago she was diagnosed with congestive heart failure, told she had 12 months to live.



Life is getting smaller and harder. Fearful, she cancels a long-planned vacation. "What if something really awful happens?" she asks. "What if I push myself so much that I take a turn I can't come back from?"

She plans her death: At home. No ventilator. Her carpenter friends build her casket, load it into her husband's van, head off to the cemetery. One afternoon she drives her dog to the park, feels the sun on her thin face and thinks, This is enough.

On this night, though, her life is not enough. Nowhere near enough. "Before I got on the prednisone, and I was having a hard time breathing, I was thinking, 'Oh my God, the last thing I could do is have any kind of sexual encounter. When I even ate something I was out of breath. So how can . . ." Her voice is pierced with longing.

## Session VII

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I am looking at the official form, having some trouble filling it out and wondering why. It's pretty self-explanatory, four pages long, handed out at the beginning of our session on legal affairs. Called the "durable power of attorney for health care decisions," it is the dying person's best friend.

The goal is simple: You write down how you want to die. You pick a person to be your champion when you are no longer able to communicate. You explain your wishes to your doctor, put a copy in your medical file, break the news to your family and the advocate you've chosen. Then, when the end comes, you can rest relatively safe in the knowledge that you have done what you can to die the way you want.

The California Medical Assn., which distributes a widely used version of the form, even spells it out for you. All you have to do is initial the part that says: I do not want efforts made to prolong my life and I do not want life-sustaining treatment to be provided or continued . . .

I do not want to die like my father. Kidney failure had sentenced him to years of dialysis--four hours a day, three days a week, hooked up to a machine that cleansed his blood. A lifetime of Marlboro Reds, then Marlboro Lights, then low-tar-and-nicotine Nows had pretty well pulverized his lungs.

He had fought off cancer some 15 years before, but could not overcome the stroke and congestive heart failure that slammed him into a hospital bed in the spring of 1995.

Unable to breathe without a ventilator. Unable to endure the pain of the ventilator without morphine. Tied to the hospital bed so that he would not tear out the offending tubes. The doctors: He will never breathe unaided again unless we do something. "Something" is heart bypass surgery on a ravaged body barely clutching to life. He dies two days before.

I do not want to die like my father. But for the first time, I understand my stepmother and sister, who grasped at bypass surgery as a way to save his life. Let me control my end, I've always thought, let me go before I turn into something--not someone. But here I am, balking at this piece of paper and thinking: Maybe there could be a miracle. I sign the form.

## Session IX

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We come bearing homework. The assignment: What would you do in your last six weeks of life? The first five you would be ambulatory and relatively well. The last one you'd be in bed, but lucid.

Ellen wants to rob a bank. Sandy wants to travel--to Greece or Egypt, then New York, then Florida, then she'll rent a red car and drive to Missouri. Jennifer, infected with HIV and newly 30, wants to ride her motorcycle up the Sonoma County coastline.

When was the last time you did that, asks Wagner. And why don't you do it now? Here, it seems, is the crux of our 10 weeks together: Why don't you do it now? Give yourself the gift of a conscious end, the calm of well-ordered affairs, the solace of reconciliation, the peace of knowing that you need not die in pain, the comfort of a life well lived. Why don't you do it now?

Paul, 80, is having none of it. What would he do with a six-week prognosis? Get a second opinion and then a third, he says, and we laugh. Then he'd take care of his paperwork. And then he'd go sailing. He wants to go back to Ohio, see old friends. Sophia, also 80, doesn't want to go, but he will not go alone. "We'll work it out," Sophia tells us gently. They usually do.

She's the instigator, he says, and I'm the modifier. She is the healthy one. He is not. She is the one who is ready to go. He is not. It was Sophia's idea to join this group. Paul came along.

It was Sophia's idea to move to the retirement home. Paul wants to stay in their house. We'll do a three-month trial run, she says. It'll be like a cruise. We hear their back and forth every week as they go through the hurdles to gain admission. What if I pass the physical, and she doesn't? They both pass.

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"We went to a memorial last Wednesday," Sophia says in early November, when we meet to talk one afternoon near the end of the sessions. "Two of our neighbors have died recently, and two are in nursing homes. One of the reasons we're going to Heritage House is because of the social stimulation. Everyone we know is dying."

The three of us sit in her family room, stripped of everything but a few chairs, a bookcase, family portraits painted in oils. If you want to see our things, she jokes, go to our children's houses. What's left here is what they didn't want. Sophia has stopped reading newspapers, doesn't watch television, announces that she's started disengaging, slowly stepping back from life. "I'm not going to call 911 for you anymore," she jokes to Paul. "I'll get a cell phone," he laughs.

We walk from their house to the No. 6 Parnassus bus stop. The air is cold, the memories warm. There's the house they could have bought for \$14,000 in 1951, if only Paul had made more than \$3,000 a year. It just sold for \$1.1 million. And look, that's where Elsa used to live. She was a social worker just like Sophia. She died. Was it this summer?

Sophia, merry in a green beret and a plum-colored coat, helps Paul put on his Windbreaker. "We've been debt-free since Oct. 10, when we sold the house," he says. "It's a good feeling," she says. "It only took 80 years," he says. "So I guess we are getting ready for the end," she says.

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We are all still around. Our final session has come and gone--an evaluation of the last nine weeks, quiet goodbyes, almost anticlimactic. We resume old lives equipped with new tools.

Jennifer has gone skydiving for the first time. "There I was, hanging out the door, attached to this guy," she recounts, breathless. "Then I was flipping. Ground. Sky. Ground. Sky. It was really remarkable."

Adina's beeper has not gone off, forcing her to decide whether to risk a transplant that may--or may not--help her live longer.

Paul and Sophia remain--so far--in their home of 52 years. They've made another visit to Heritage House, admired the Christmas ornaments in the graceful lobby. "We told them no," Paul says. "No, we didn't," smiles Sophia.

PHOTO: Paul and Sophia, 80, above, gave away many possessions, but kept family portraits.; PHOTOGRAPHER: LUIS SINCO / Los Angeles Times; PHOTO: Richard Wagner, left, started the classes after losing many friends to AIDS.; PHOTOGRAPHER: LUIS SINCO / Los Angeles Times; PHOTO: HIV-positive Jennifer, right, wants to take a long motorcycle trip.; PHOTOGRAPHER: LUIS SINCO / Los Angeles Times

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