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FROM THE INSIDE OUT: The culture of dying in U.S. retirement communities

The way you know you're dead, in a U.S. retirement community today, is when your picture goes up on the table in the lobby. Until that moment, it is something you don't talk about.

There are, indeed, related things you *can* talk about. Hospice. Long-term care insurance. Disability rights. Advance directives. POLST forms (Physicians Orders for Life-Sustaining Treatment; we'll talk more about that later.) But what you still don't talk about are the topics that force talkers to contemplate the fact of their own impending demise. Hastened dying? Never. Written declarations as to emergency situations? Tricky. Cremation plans? Heavens no.

The lines between acceptable and not-acceptable conversations are thin, but steely. It is permissible to ask, "Have you signed a DNR (for Do Not Resuscitate,) or a form saying No heroic measures?" Pleasant, generalized conversations may follow. But one should avoid asking – when a dying friend is seen being loaded into an emergency ambulance – "Did he have documents saying he wanted to remain at home and not be taken to die in the emergency room or ICU?"

This paper takes a close-up look at two California urban retirement communities and the ways their residents do – or do not – consider the event that results in the picture going up in the lobby. For purposes of clarity – and to keep the author out of big trouble – they will be known as The Oaks and The Ivies. The Oaks is a church-affiliated highrise with some 300 units ranging from 400 square foot studios to spacious two-bedroom/two-bath apartments. As a "Life Care" facility, it features separate areas for assisted living, nursing care and dementia. You pay a chunk of money on entry, and whatever needs you might encounter before you die will be accommodated in one area of the building or another. In other words, as my Parkinson's-afflicted brother-in-law famously remarked when he and my sister moved into a similar facility in New York about eight years before he died, "They can't throw us out."

At the Ivies, they can throw you out - - or at least subtly edge you out. You buy your own condominium in this 92-unit building, while simultaneously buying into the management system that runs the place – including a "Wellness Center" with an on-call doctor, a social worker, nurses and a constantly fluctuating staff of "Certified Nursing Assistants." The latter will come to your apartment and help with virtually anything you need as you decline. If you get to the point of needing 24-hour care, as long as you can afford to bring in a private caregiver for that, all is well. But if, say, you start wandering around and are deemed to become a danger to yourself or others, you will gently but firmly be asked to find more appropriate living arrangements. Still, just as with the residents of The Oaks, people who buy into The Ivies do so, 99% of the time, with the intention of going out feet first.

Why, then, is it forbidden to talk about going out?

This situation happened to this writer. I've lived at The Ivies with my now-wheelchair-bound husband for five years. A neighbor, who had been in failing health for several years and was receiving the highest "level of care" available, spent the last year or so of her distinguished life – she had been a successful businesswoman and philanthropist – essentially out of touch with reality. Before that time, she had repeatedly said things like "I don't want to die in some sterile

ER with wires and tubes everywhere." To which I regularly replied, "Have you talked to your daughters about that?" – or – "Do you have that written down?" To which she regularly replied, "Oh, they know!" When she had her final "episode," she was wheeled off to the Emergency Room, as is the policy of most retirement communities, where she was intubated and connected to countless wires and tubes until her daughters eventually showed up and declared that enough was enough. But her dying process all told extended into three painfully uncomfortable, expensive days.

Here's the dirty little secret: even in retirement communities where private conversations can be held – between residents/prospective residents and management – about specific wishes for one's demise, public conversations remain a no-no. Thus, issues go unspoken and un-addressed, and families encounter death as if it were a giant surprise.

There's an interesting, and indeed logical explanation. When you move into a place like The Oaks or The Ivies, you're usually still upright and active. You're moving in to be there for the rest of your days, but at move-in time those days don't seem stingily numbered. You're looking at the lifestyle of the place rather than the eventual die-style. Management encourages this, because it brings in the customers. Management also wants you to be fairly perky on entry; especially with the Life Care places, the less time you spend in nursing or other labor-intensive care the better their bottom line. My husband and I were, in fact, turned down by The Oaks; he was walking with a cane, but not moving fast enough.

From any angle, dying in the U.S. is simply taking longer. At The Ivies, extended dying is in fact a bonus for management, as they tend to make more money on the higher levels of care. But virtually every retirement community in the U.S. puts 99% of its advertising energy (and budget) into that "Active Living!"/ "Fun in Retirement!"/ "Luxurious Maintenance-Free Lifestyle" general theme. The Ivies bills itself as a "distinguished boutique retirement home community," although I generally, and in my opinion accurately, refer to it as the geezer house.

One underlying reason – though hardly an excuse – for the shroud of silence surrounding death and its implications is the simple fact that prospective entrants prefer to talk about the lifestyle amenities – and not the deathstyle details. "You mean, I'm going to DIE here?" "Well, yes, actually. Isn't that why you're moving in?" That exchange does not take place. Instead, when soliciting new purchasers or new clients, the talk is all about amenities: Yoga classes, book groups, political discussion groups, movies, wine tastings . . .

A good friend of mine is a classic example of the perfect retirement community newcomer. She moved into The Oaks eight years ago when she was in her mid-60s. Smart, fit, active and energetic, she was soon elected head of the Residents Council. Her reasoning for moving in was that she loves to travel and wanted to be free of home-owning responsibilities. She thought it seemed a great idea to commit to a Life Care facility while comparatively young so she wouldn't have to worry about home maintenance, cooking, or potential healthcare needs ahead. Yes, she planned to die there, but at least several decades later. So she signed a contract involving a chunk of money up-front and sizable monthly fees – but they could never throw her out. In between travels, she soon grew bored with the less-than-wonderful food and weary with the unending details of the Residents Council. Her term as president ended two years ago, and although she continues to be an active participant she was delighted to ease out of those often petty-seeming responsibilities. In the past three or four years, however, she grew particularly weary with watching friends in The Oaks become feeble and die. Six months ago she bought a 3-bedroom home across the country (near her son,) swallowed the considerable loss of her down payment for The Oaks, and moved.

My great good neighbors at The Ivies made a similar decision last fall. A couple still active in their 70s, they got tired of being surrounded by walkers and wheelchairs and caregivers – and watching friends at The Ivies die. They sold (to a widow in her early 80s whom, happily, I like a lot) and moved across town to an apartment near their children.

The above examples point to an increasing fact of retirement community life: the communities desperately want to be about "active living," but more and more they are simply about prolonged dying. The median age at The Oaks a decade ago was 75; today it is 85. I asked for (and quickly got!) a meeting with the Executive Director and Sales Manager of The Ivies not long ago, to beseech them to find buyers who are still active and engaged. I am on the board of the Homeowners Association. Within our 92 units, it has become increasingly hard to find people for board positions and essential committees. My management friends said, optimistically, that these communities go through cycles and as units change hands The Ivies will once again become the more vibrant community into which my husband and I moved five years ago. Well, bull. The reality is that people are waiting longer to move into retirement communities, and those who are there are taking longer to die. In other words, the population undergoes a constant shift toward people in decline. And decline, at some point, leads to this: you die.

Still, nobody wants to talk about it. My husband and I, some time ago, carefully researched the bewildering assortment of cremation plans available in our area. We decided on one company that seemed very reputable and offered a few of the details we sought: some veteran's benefits for him, an assurance for me that if I died in Timbuktu – I still enjoy traveling and hope to continue as long as I'm able – they'd pick me up and ship my ashes home. Feeling pleased with ourselves for completing these arrangements, we suggested to the Activities Director that the cremation society representative we dealt with make a presentation at The Ivies. We had picked up a few helpful tips along the way, such as: put your cremation society membership card behind your driver's license and if you're hit by a Mack truck at least your family won't have to deal with (and pay for) the hospital morgue. Not everybody opts for cremation, but we thought a presentation could still be widely useful.

"Oh, no!" said the Activities Director. "Nobody would come to something like that!"

He knows whereof he speaks. My nonfiction book *Dying Unafraid* was published in 1999. Although it's had a respectable outing and remains in print, I learned early on that book events at senior communities or retirement homes were out of the question. The manager of one such place, asked by a friend of mine if he could arrange a book event there, said these words: "We aren't interested in things like that; it's too morbid."

I have no scientific explanation for the morbid fear of mortal discussion among the elderly, but it may be this: When you're young – say, under 40 or so – you generally don't think about your own mortality because you think you're immortal. Why else would anyone skateboard through rush hour traffic or play games with dangerous drugs? Up until a certain age, about 60 or 65, it's possible to think about death and dying as something that happens to other people. As one edges into the Golden Years, the issue slowly morphs from the abstract into the concrete. And simultaneously, there is a growing notion that talking about mortality might suddenly make one – well, moribund. In retirement communities this notion seems to be magnified in direct proportion to the median age. It's as if the closer we get to dying, the more determined we are to ignore it.

The costs of ignoring our impending demise are staggering. Not just in monetary terms, but in physical and emotional impact on friends, families and on us, the dying. Frank and open

conversations with physicians, family members and friends are the first best ways to confront one's own mortality. Other guarantees of the kind of dying one would choose include writing advance directives, signing POLST forms (a standard form signed by one's physician outlining basic end-of-life treatment agreements,) completing (and talking about!) other documents like dementia-provision clauses, DNRs, refusal of feeding tube, and simple personal preferences. It's not happening. Here are just a few of the realities of our culture of dying:

Nine out of ten people in the U.S. say they would prefer to die at home. Seventy percent of us die in a hospital, nursing home or long-term-care facility. Half of us die in hospitals.

Virtually everyone says he or she doesn't want to die while hooked up to wires and tubes in a cold, sterile cubicle. Twenty percent of Americans die in hospital intensive care units. The cost of such unwanted, futile treatment runs anywhere from $5,000 per day up – with virtually no real ceiling to the 'up;' the physical and emotional cost to patient and family is immeasureable.

Even with some hospital admissions requiring a patient to have such documents, fewer than a third of Americans report having an advance directive or living will. Among those who do, only a quarter of their physicians are aware of their patients' advance directives.

And not to be crass, or anything – but annual U.S. critical care medicine costs, according to a study more than a decade ago (which suggests you could double these figures today) increased from $56.6 billion to $81.7 billion. That's *billions*. Thus, if perhaps a few thousand people could die as they say they'd prefer we would save a few billion in the bargain. It will never happen until Americans admit their own mortality – their own inevitable dying – and demand a say in their options surrounding it.

In retirement communities, the popularity of yoga groups, mindfulness seminars and meditation classes grows by the day. Maybe the answer to this population's ongoing denial of death will be to sneak the unpopular topic into those popular activities. That could be a way to follow the late Italian novelist Umberto Eco's wise words: "It is necessary to meditate early, and often, on the art of dying to succeed later in doing it properly just once."