

"Dying in America," address given at UB at Sunrise Breakfast, Center for Tomorrow. State University of New York at Buffalo, November 17, 1994.

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by

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Good Morning! When I was asked to talk on the subject of Dying in America at a breakfast meeting, It occurred to me that I might get to make some wisecracks about how we eat, at a breakfast where we would be served croissants, butter, sausage and eggs, and berries served with Devonshire cream: certainly the most tasteful form of dying in America! Nor have we been disappointed: quiche and ham should do quite nicely.

Then, after last Tuesday's election, someone approached me and asked if my talk was going to be on Democratic Party politics. I suppose the title "Dying in America: might fit that subject very nicely! Another wag asked whether I was going to discuss the Buffalo Bills' current football season

All of these possible applications of the phrase "Dying in America" point to the enormous importance we attach to the idea of dying, and the ways we use that idea in our very metaphorical language. That kind of richness of language is a sure sign, as Joseph Campbell would remind us, that culturally pervasive myths are constructed around the idea of dying.

Now, I don't intend to talk about Campbell's views at all today, and I will avoid a short course on myths. But I will make just one or two observations about myths so that you are not uncomfortable with my later use of the term. For one of our myths about myths is that, in this educated and scientifically literate society, we don't have any myths; myths are supposed to be the glue of fictional beliefs that holds primitive societies together, and we certainly are not primitive. Well, let me explain how I intend to use the idea of myth to illuminate some of our values and practices associated with the idea of dying in America.

First, by a myth I mean a culturally pervasive set of beliefs and values that tends to center on a single, simple archetypal image or scenario. And second, by calling something mythic I mean to invoke perhaps a number of myths operating as a cluster of culturally important determinants of attitudes and behaviors. My ultimate goal this morning is to review our myths about dying and some things Americans are doing to achieve some control over the final days of their lives.

During the course of my 50-odd years, I have witnessed a shift in our myths about dying in America. I want to characterize this shift by describing two scenarios that seem to capture the shift I refer to. The first scenario is a classic, perhaps Victorian one. The scene is cast in the master bedroom of a squire in an English country manor house. The room is darkened by heavy velvet curtains, drawn against the bright day. The dying squire lies on a soft feather mattress in a four poster bed with a canopy of the same velvet; curtains for the bed are pulled back from the foot and sides against each of the posts. To one side of the bed sits the physician, wise, somber, a pocket watch in hand as he takes the pulse of the squire. To the other side is the daughter, sobbing quietly, holding the squire's other hand, face buried in her arms encased in the crisp, white, starched blouse she wears. At other places around the room stand or sit other assorted relatives, friends, and servants, all waiting to provide witness to the final aspiration.

The squire rallies a bit, asking for a sip of water and for the pillows to be plumped behind so as to prop him up a bit. The doctor nods gravely to those assembled, bidding them to draw closer. In a thin but clear voice, the squire calls each servant, friend, and family member forward, to bestow legacies and pensions and otherwise to distribute his estate: 100 pounds Stirling a year for life to the valet, five pounds per month to Cook, a favourite hound to the Gate Keeper, a brace of dueling pistols to an old enemy turned friend, and so forth. A tightly-run trust for the somewhat profligate son; the house and grounds to the daughter.

The squire falls back, his duties now complete, and over the next hour, breathing slows, becoming more and more shallow, until the final death rattle shudders through his body convulsively. The physician's head bows; his ear is placed next to the squire's chest for a full minute. He rises, puts his watch back in his pocket, and his hand passes over the squire's face, closing the eyelids. A collective sigh escapes around the room; several women burst into tearful wailing. A sheet is pulled up over the squire's head. Death has come quietly and just as quietly stolen away with its prize.

That was the myth, the ideal, the image of dying that I and many in the room grew up with. I don't mean all the trappings of the manor house and servants, but I do mean the ideal of death coming upon one in good time, in one's own bed at home, quietly, with plenty of advance notice to permit loved ones to gather and take their fond leave. The function of medicine was that of a knowledgeable and wise advisor.

Modern medical technology and our thirst for it have replaced that myth about a good death with another. This is very much our current cultural image of what a good death would be like:

The trim, tan, handsome couple returns to their condo in Sarasota after two sets of tennis in which they have thoroughly trounced their great-grand children. He is 93; she 90; he has had two heart valves replaced and , later two total heart transplants; she has had a triple bypass every seven years since she was 68, and shrugged off the ravages of 30 years of smoking with a highly successful total lung transplant. He has had total hip replacements twice on one side and once on the other; she has had cataract surgery. Both wear the latest subdural hearing aid implants. She still sports estrogen patches, visible as she teasingly undresses.

They shower together, as has been their custom for the 70 years of their marriage, soaping one another vigorously. After drying off, they fall into bed and make love passionately, each coming to climax twice. They rise, put on thick, white terrycloth bathrobes, and proceed to the terrace where their mid-morning brunch of fruit salad, french rolls and cheese, and champagne cocktails, their children, grand-children, and the abashed and adoring great-grandchildren, await them in the brilliant sun. Each enjoys the meal hungrily, chomping into the French bread and goat cheese joyfully with their perfect teeth, the result of modern dental implants. The grand kids indicate they are off that afternoon for their last vacation before entering the work force, after which they face 50-60 years of unremitting toil before they are rewarded by retirement in their 70s or 80s. The children and grand children are about their various tasks in their one-day-a-week off, before returning to the long workweek necessitated by the burgeoning social security tax, now well in excess of combined state and federal income taxes.

The passions of the morning return to our old couple, and with twinkles in their eyes, they return to the boudoir where, with a passion reminiscent of something Glenn Close and Michael Douglas might portray, they strip one another and lock in an embrace once again.

Just at the moment of peak pleasure, a look of astonishment crosses both their faces: their arms tighten one last time around each other, and then they drop to the floor on either side of the bed, their hearts having stopped

simultaneously. The clock reads 11:00 a.m. on that sunny Sunday morning, and somewhere above a pair of gulls cry raucously.

Now, the image of death in this metaphor is that of the one horse shay: parts replaced as they wear out, the whole carriage kept going until the moment when its age will no longer sustain it, and total, immediate, and sudden collapse. And no doubt something like this myth has been driving some of our practices in recent years. Were reality close to the myth, about all we would have to worry about is the bill for social security and payments to and from Medicare.

But another, darker mythic scenario also clamors for our attention.

In this scenario, the final chain of events begins, as in the scenario just above, with a sudden collapse of an apparently healthy person. But it differs in that the collapse is noted, usually by a relative. Our initial instinct, conditioned by media but reinforced by the normal expectations of loving care, is to call 911. Emergency medical technologists who respond to such calls do so under a rigid set of guidelines and a narrow set of options. So, whatever the crisis, life is sustained and death kept at bay. The collapsed shay is reassembled. Only now, it is no longer road-worthy. The re-started heart has been not beating long enough that irreversible brain damage has occurred. The fall from the bed has fractured a hip, or a shoulder, or an elbow. The following hospitalization is characterized by a series of crises, a series of cardiac arrests, wild fluctuations in blood chemistry, opportunistic infections in skin and lung. The loving family, perhaps made guilty by harbored feelings of resentment that they have to work so hard to support the social security system, present themselves at the bedside insisting that everything be done for their parents, rebuffing suggestions that perhaps this is the time to think of DNR Orders and move from a cure orientation to a care orientation. A small stroke robs the mother of the ability to swallow; a feeding tube is ordered. The father is in a somewhat vegetative state, with tubes entering or exiting nearly every orifice, IV lines in each arm, restraints on the wrists.

Recovery is sufficient to move them from the ICU into the Skilled Nursing Facility, and they receive the appellation of “GOMERS” from the more jaded resident physicians (a term that has entered our vocabulary as the result of the all-too-realistic mythic novel, *The House of God*, by Dr. Samuel Shem). Perhaps they become well-enough managed that they can be released into the care of the family and returned home. Demented, helpless, they require then the resources of the family, often in the form of a younger female member of the family devoting herself to the daily needs of the aged infirm. And, because their wishes regarding care and treatment options can no longer be determined, families and health care providers become locked into a persistent expenditure of personal and societal resources to the end of keeping the aged person alive. When death finally comes, weeks, months, even years later, the enormous toll that is paid by care givers and society feels like the paradigm of futility.

There is another myth that has sprung up in our thinking and talking about what to do about the health care crisis. This myth has it that (the percentages vary depending on the source of the version of the myth) up to 90% of all health care dollars (a more reasonable version is all medicare dollars) spent on a person in his or her entire lifetime are spend in the last (again the time period varies) month/three months/ six months of life in futile attempts to extend it. The myth continues, “If we could but identify when a person is going to die, and suspend the use of life-prolonging technology at the start of that final descending spiral, we could reduce the amount being spend from 14% of the Gross National Product to something like 5% or 6%. And that would, of course, solve — or at least put off for another generation or two — the health care crisis.

These last two myths —that about the ways we often end up dying horrible, lingering deaths, and the possibility of solving the health care crisis by avoiding medically futile efforts at extending life — have prompted a growing number of Americans to embrace yet another myth. This myth is a variant on the first one;

only, instead of the physician assuming a watchful role in witnessing death's final event, passive except for shepherding the assembled family and friends through the ritual of last leave-taking, the physician is now asked to assist in the timing and character of death.

I do not mean to restrict these myths to the elderly dying. The scenarios, with suitable alteration, apply as well to middle aged adults and even to children. If we could but know that we aren't going to recover, and if we had in our hands the means for ending pointless lives then they have lost their point, we could (so the myth goes) solve the health care crisis and avoid the agony of months or years of pointless, suffering existence. I think it is something like this myth that has prompted the voters of Oregon recently to pass a referendum which, enacted into law, would permit adults expected to have less than six months to life to request and obtain prescriptions from doctors to end their lives. Dr Jack Kevorkian, of course, would like even greater latitude given to the notion of terminality: on his view in the book, *Prescription: Medicine*, he supports physician assisted suicide for patients who are "mentally terminal" — that is, who face irreversible loss of mental capacity. The Oregon initiative does not explicitly address such cases, but my guess is that, if the practice of physician assisted suicide is passed into law, pressure will grow for extensions of it into the range of cases envisioned by Kevorkian in his dealing with the 1990 case of Janet Adkins, diagnosed with Alzheimer's disease.

Underlying the Oregon initiative and Kevorkian's views is yet another mythic idea. This idea, interestingly enough, has a grammatical component. It is the idea that "to die" can become an active verb rather than a passive one, that "Jones" died can become more like "Jones voted" than like "Jones was surprised the Bills lost." (Jones, you may conclude, has not been watching the team play in recent weeks.) This mythic idea holds up the possibility that dying can be something we do, not something that only just happens to us. And it responds to the underlying fear that dying can be made enormously protracted and unpleasant by modern medical technology, that the dying and thus loved ones are sometimes locked in a struggle with the institutions of medicine, geared as they are to prolonging life and holding death at bay at all costs.

In New York State, our visions of dying have so far evolved into DNR orders and Health Care Proxies. I sit on several hospital ethics committees. The chief issue which comes before us over and over again is the question of what the incapacitated patient's considered wishes would be. The proxy can solve that and solve it definitively, particularly in the face of family conflict or disagreement with or among health care providers.

My own preference among the myths we have discussed is for the Victorian model first discussed. Let us restore the tradition of witnessing death as a natural part of life, occurring where life has occurred, at home, or in hospice in a home-like setting, amidst family and loved ones, with no imposed visiting hours, handing over legacies, taking leave of family and friends.

Dying at home: you ought to try it sometime!