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Lowell Student Speaker Series
February 13, 2011
"Death and Other Upbeat Topics"

Good evening. I want to thank Sandy Alexander for organizing this wonderful enterprise, second best in my mind only to the time that Sandy coerced me and several others into helping him extract a plastic bag from a tree in Lowell courtyard. Being Sandy, though, a ladder was just too easy – instead, he insisted on devising an elaborate pulley system involving fishing wire, the bell tower, a brick, and duct tape. I thank Sandy also for providing constant encouragement and feedback as I wrote this speech. Thank you also to Susanna Mierau, who, over cups of tea, has on many occasions kept me in the dining all much longer than I should have been, and has taught me much about the complexities in these issues from the perspective of a physician.

I dedicate this speech to Susan Hamburger, a woman whom I did not know all that well, but taught me something important about love. And to her son, my best friend Ellis, who continues to inspire me and show me meaning everywhere in life.

During dinner one night over vacation, I decided to engage my family in a discussion of the topic for my Lowell House speech. We began talking about health care spending at the end of life, approval for experimental treatments, and the rhetoric surrounding "death panels" that was the hallmark of the health care debate last spring. My father, the lawyer that he is, posed a hypothetical: If he were 92 with terminal pancreatic cancer, would I not want him to have access to every therapy available, cost effective or not? Of course I did, I thought to myself. But my hesitation in answering was enough. Quickly, he turned to my older brother and said, “Daniel, you and *only* you will be in charge of the medical decisions when Mom and I get old.”

I’ll note also that I am the one who did the dishes that night.

While my dad was only joking (and didn’t disagree with me as much as you might think), I think his point reflects the prevailing wisdom amongst the vast majority of Americans today – that the goal of the health care system should be to aggressively treat illness until all options are exhausted. That there is always something more that physicians can do. AND – that the goal of the health care system, above all else, is to prolong life.

If I were an economist, at this point I would throw a bunch of financial statistics at you – I’d talk about the unbelievable rate at which medical care spending is growing in the US, the higher spending in the US relative to Western European countries that achieve better outcomes, or the alarming portion of that spending that occurs in the last months of life. But those facts are not my focus tonight.

Instead, I want to talk with you about the social experience of dying. About *how* people die – who is near them, how they feel, and what they know.

A powerful fact about dying is that almost all of us want the same few things when we die. 90-95% of Americans say the following things are most important to them at the end of life: being free of pain, not being a burden to their families, having a doctor who listens, and knowing what to expect. And a tragic fact about dying is that most of us don’t get what we want. Only 45% report not being a burden to their families, 40% having a doctor who listens, 35% being free of pain, and worst of all, only 15% claim they know what to expect when the end is near.

In a widely read and discussed article in *The New Yorker* this past summer, surgeon and public health advocate Atul Gawande writes about the process of "letting go," arguing that there is a deeply ingrained cultural instinct to prolong life. "our every impulse is to fight," Gawande writes, "to die with chemo in our veins or a tube in our throats or fresh sutures in our flesh. We fall back on the default, and the default is: Do Something." As he recounts the horrific stories of numerous ICU patients whose last days of lives had been ruined by loved ones who couldn't let go, he laments that "Almost all these patients had known, for some time, that they had a terminal condition. Yet they—along with their families and doctors—were unprepared for the final stage." Though Gawande doesn't say this, the implication seems to be that, as a society, we think love at the end of life means pushing and pushing and not giving in. Can this really be?

When I was 12 years old, my best friend Ellis' mother Susan succumbed to the brain tumor that had been slowly killing her for nearly a decade. She was 42. Susan was a strong woman and someone who "fought" in the way that we want our loved ones to fight disease. Given just a year to live, she beat the odds and lived eight. But when the end was in sight, she approached death with dignity; she sought hospice care in her home, brought loved ones close, spent time with her husband and her young sons, and soaked up the goodness of her friends. Ellis doesn't remember much about that time, but he does know that his mother *lived* the last months of her life. That she died without pain. That she knew what to expect and what was coming. And perhaps most importantly, he knew that his mother didn't give up in the face of challenge – that she lived, and died with grace. And the words she wrote in her final letter to her son were a testament to her sense of valuing what really mattered. “Love your brother,” she wrote – “take **care** of one another.”

How should we take care of someone we love when she is dying? It is tragic to even suggest that there is a “model” for dying. Dying is a process that is so deeply and intensely personal bound up in religion, spirituality, and the intricacies of our individual experiences and personal narratives. It sometimes comes after years of illness, and other times strikes suddenly and unexpectedly, as it did on this very campus but a few hours ago. But what Susan taught me in those last months was that that in the final moments of life, one has to *live* and not just put off the inevitability of mortality.

I have attempted to approach this topic with humility. With the knowledge that I have never suffered serious illness or cared for a dying loved one. I have not spent the long nights in hospitals, crouched awkwardly in the armchair attempting to grab just a few minutes of sleep before the sun’s rays peer in from over the horizon. I have not held the hand of the sick one and told them that it would be alright, with the full knowledge that it really wouldn’t.

But I hope that above all, you leave tonight not with answers, but thinking about this: What does it mean to care for our loved ones when we know they are going to die?