

## Musings on Mortality: Death-phobic culture hinders end-of-life plans

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My first experience with how unreasonable our culture is regarding death came after the birth of my irreversibly brain-damaged daughter (due to medical malpractice) and how obvious it was to me, my husband and our extended families that the best outcome would be for her to be allowed to die.

We were not, however, met with the same conclusion from the urban hospital whose neonatal intensive care unit she was transferred to. Legal considerations and unresolved legal precedence on a national level were the crooked light through which our baby's fate was seen — what a wake up call! Then in my 40s, my seemingly healthy and vital husband was diagnosed with metastasized pancreatic cancer. It was in no uncertain terms a death sentence, but an oncologist suggested chemotherapy. Why? Because, except for the metastasized cancer, my husband was "young and healthy."

What I learned then was that in our culture, treatments — even if they are futile — are not offered as an option, but as a given. To turn them down is to be a failure to oneself and one's family. One tries everything to survive, no matter how dire the prognosis.

In the summer of 2013, my 86-year-old mother took her own life in the independent facility she had impulsively moved to. Once she made the decision, she planned her suicide as she had lived her life, meticulously and in control, leaving detailed instructions for me to follow and hand-written notes to mail to her friends and relatives. What I didn't count on was the decision by the facility to not tell the residents of the circumstances of her death. They were going to lie about how she died.

They said it would "upset" the residents to know the truth. Upset the residents!? These were people as old as, if not older, than my mother, many teetering on their last days.

These were adults, not children. I was adamant that the reality of her death be known and that my mother would have insisted. At the coroner's office, I

was told death by suicide among the elderly is much higher than we think but no one talks about it and it is not explicit on the death certificate.

I have been teaching medical ethics and subjects in thanatology for many years, and I have learned a great deal from my students, research and observations. I also learn so much by approaching these topics with anyone who cares to be engaged. I have found there is great confusion, misinformation, anguish, unresolved issues, false notions, and a perpetuation of the body against all reason that just about everyone I know is grappling with. If they are not grappling with their own aging bodies, then they are tormented by what to do and not to do for their parents and spouses.

Recently, I was told by an ailing relative in his mid-80s that while he knows he is dying, he "can't die" because his wife needs him to live. This is not an uncommon position assumed by the dying, but is it mature thinking or the result of a lifetime in denial? My hope for this monthly column is to explore the prevailing issues in the world in which we find ourselves and have created: a death-phobic culture dominated by medical technology and the imperative to live as long as possible.

Everyone claims to want a good death, but very few of us have one. Why is this the case? How can it be different? My intention is to help us navigate the mortal landscape and to, against all odds, prepare for illness and dying for the sake of ourselves, loved ones and future generations.

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