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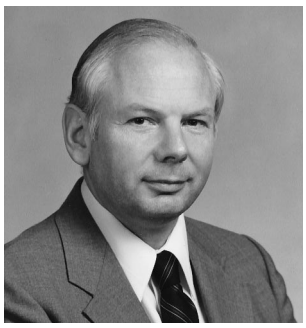
EDITOR'S PAGE



End of Life Decisions—Personalized

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The airplane drones eastward at 37,000 feet and 560 miles per hour. Usually when I find myself in this position I am reading a series of manuscripts submitted to JACC to prepare for the next weekly editor's meeting. This time, however, as Co-Chair of the ACC's Second Bethesda Conference on Ethics in Cardiovascular Medicine, I am reading a draft copy of the report from Task Force 2—Application of Medical Interventions Near the End of Life.

> Cast me not off in the time of old age; forsake me not when my strength faileth.
>
> Psalms 71:9

Several paragraphs catch my attention:

> Covert rationing based on ageism, i.e. a tendency to regard older persons as debilitated or unworthy of attention, is manifested as withholding appropriate care for medical reasons. The elderly may be particularly vulnerable to misleading representations regarding the hazards and futility of complex medical interventions . . . .
>
> The always difficult distinction between critical and terminal illness is more difficult as patients near the end of their natural lives . . . Family members motivated by guilt rather than compassion, may insist on aggressive care with little chance of success.
>
> Futile care is that which provides no benefit to the patient or which has proven to be useless in achieving its desired effect. Family members often have difficulty being objective when making informed choices about futile care of a loved one. Decisions are often influenced by love, feelings of guilt, fear of loss or loneliness, or by self gain.
>
> During the past twenty years a standard of practice has emerged that recognizes the right of patients to forego life-sustaining treatment even if this results in their death. This includes the right to withhold (not start) or withdraw (stop) cardiopulmonary resuscitation, mechanical ventilation, dialysis, antibiotics, and artificial nutrition and hydration. This right is grounded in the ethical principle of respect for patient autonomy and protected by the legal doctrine of informed consent.

I finish reading these excerpts and the rest of the document on end of life decisions as the plane begins its descent into the Salt Lake City International Airport. The poignancy of the moment is almost overwhelming, as I ponder why it is so emotionally difficult to personalize these principles.

One hour later I am at the bedside of my father who is a few weeks short of his 100th birthday. Hospitalized for an infection, now controlled, he is in a rehabilitation center, when he has a stroke 2 days earlier, affecting his ability to speak. I learn on arrival that he has just had a barium swallow, which shows considerable aspiration into the lungs, no matter the consistency of the fluid. It is decision time—a nasogastric feeding tube or not. As I listen to his garbled speech, which is barely understandable, I remember his erudite and technical conversations about the principles of physics. In just a few weeks we had a large family birthday party scheduled for him. Family members around the country had arranged their vacations months ago to come to this event. Because the University of Utah celebrated its 100th year, he had been named the Centennial Professor, and a separate birthday reception was planned by the physics department. Oh how he was looking forward to those two celebrations. Oh how the family was looking forward to his 100th birthday celebration.

Now it was time to discuss the medical question at hand—a feeding tube or not. I try to objectively present the discussion, keeping in mind the three elements of disclosure, capacity and voluntariness. There is no question about his ability to understand the options: His mental capacity remains sharp despite his garbled speech. As the discussion ensues, I dread the inevitable question: "Bill, what do you recommend." I control my feelings as best I can and tell him that we want to follow his wishes. The discussion goes on that evening and the following

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morning. His mind is clear and he reaches his decision: He does not want the feeding tube; he wants to go home and die there with his family around him. His quality of life had approached zero, so that quantity of life no longer had any meaning. He especially looked forward to an upcoming association beyond the veil of death with his wife and other family members and friends who had preceded him. I was grateful for a strong father who made the correct decision for himself and which would have been very difficult for his emotionally involved son and other family members.

End of life decisions—never easy, but incredibly important. Thanks, Dad, for being so strong one last time.