The Right to Decide

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In recent years, many friends, neighbors and colleagues have spoken with me about their concerns of how we die in the era of modern medicine.

In the mid-20th Century, Jean Rostand, a French biologist and philosopher, wrote, “Science has made gods of us before we are even worthy of being men.” If he were writing today he might have said “before we are even worthy as human beings” rather than “worthy of being men” but, in other respects, the prescience of his commentary goes to the heart of certain problematic aspects of modern medical practice.

In medical centers throughout the world, human organs – livers, lungs, even hearts – are transplanted, replaced or supplemented thanks to technologic capabilities undreamed of only a few decades ago. We must all be grateful for the extraordinary advances that have added many happy and useful years to the lives of millions.

Yet these same technologies in many instances have confronted patients, families and professional caregivers with excruciating personal and ethical dilemmas. The god-like capabilities conferred by science can enable medical practitioners to extend life far beyond the wishes of patients and their loved ones, propelling patients into a quasi-nightmare of shadow existence – not dead, but hardly living in the usual sense of that term – unable to recognize or communicate with loved ones and lacking all but the most rudimentary awareness of their surroundings.

Sometimes a physician, immersed in the medical world and impelled by a technologic imperative, urges just one more effort to defeat death, or at least to hold death at bay for a few more days, weeks or months. And sometimes a patient, persuaded by the doctor’s optimism, will acquiesce. Too often, the decision to use the full array of available tools is made on behalf of a patient whose cognitive state does not enable her or him to give meaningful consent.

This can lead the patient into the very trap that she (he) wished to avoid, connected to the full panoply of life support technology, unable (if aware at all) to muster the will to plead for a merciful end to a fruitless effort to hold death at bay. Such efforts often seem to be not an extension of life but merely an extension of the dying process. Surely such apprehensions weigh heavily on many people who have raised questions with me about how to exercise some control over the end of their lives.

What advice can one give in response to such a query? First, to discuss your wishes openly and honestly with your physician. Second, to be aware that the final decision about the kind of care
you want and do not want should be made by you – not by a physician or team of physicians – after taking into account all information provided by your physician.

The nightmare of losing one’s decision-making capacity haunts all of us and for that reason it is vital that each of us execute an advance directive – a health care proxy that designates an agent to act on our behalf in the event of our incapacity, someone who understands our wishes and will act to carry them out if that should become necessary.

This issue will demand growing public attention as modern technology continues to offer a god-like ability to extend life – or at least to defer death. Different people will approach this issue differently, but society should respect each person’s right to make this fundamental decision for herself or himself.

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