If I were to suffer from a health care crisis from which I was unable to speak for myself, who should have the right to speak for me? Common parlance suggests that the closest members of my family (spouse and adult children, in my case) should be able to speak on my behalf. This will indeed be the case for me, because I have an advance directive appointing my wife and adult children as my health care agents. For the 4 out of 5 New Yorkers who do not have an advance directive, there is no guarantee who would have the authority to speak on their behalf. Without this advance directive, doctors and lawyers practicing in the State of New York may successfully argue that no one can speak on the patient’s behalf. How might this issue apply at the bedside? Simply put, a strict legal interpretation of New York State Health Care Law precludes the discontinuation of life-sustaining and life-prolonging medical therapy by anyone who has not been duly appointed to speak on the patient’s behalf. This applies to a life that is being maintained and/or prolonged by treatments such as artificial nutrition and hydration, renal dialysis, or mechanical ventilation.

So why are New York (and Missouri) in this predicament? Because neither state currently has a Family Health Care Decisions Act. The only possible health care situation that has any hope of passing muster in these two states (where there is no advance directive) is the extremely high standard of clear and convincing evidence. Missouri’s tragic case of Nancy Cruzan comes readily to mind. Nancy’s car went off the road, and she was found face down and not breathing; she never regained consciousness. After a year of care, it was clear that she was in a persistent vegetative state. Nancy’s parents desired to discontinue the artificial feedings and petitioned the court to do so. Ultimately, the case went to the Supreme Court, which determined that the
testimony of Nancy’s roommate did not strongly represent the patient’s personal desires, and that a lower court’s demand for credible evidence was not unconstitutional: hence the establishment of ?clear and convincing evidence.?

At first blush, clear and convincing evidence (CCE) may not appear to be a particularly odious or difficult standard. After all, hasn’t nearly everyone weighed in regarding the case of Terri Schiavo and made their personal desires known? No, they have not. Or, in many cases if they have, vague and unhelpful statements such as ?Don’t you dare do that to me!? constitute the entire discussion. Statements such as this simply do not constitute CCE. For a statement to rise to the standard of CCE, it needs to have been said multiple times, to different people, over a period of time. This, as one might imagine, is rare indeed.

So, at the bedside, if one did not ? and now cannot ? speak for herself, what is one to do?

If there is no CCE, how can the medical team and the family engage in the art of medical decision-making? Most bioethicists and state legislatures have agreed to allow two other levels of medical-ethical-legal decision-making: substituted judgment (SJ) and best interest (BI). Under SJ decision-making, a decision is made using parameters, concepts, and attitudes that have been clearly documented in prior communication by the patient. In this way, the decision-maker attempts to make a medical decision that the patient would have made herself. BI decision-making is the working model when there is no other higher option, such as substituted judgment. It is applicable primarily when the patient has never had the opportunity to declare or infer personal preferences for herself. An example is a case in which the patient has suffered from profound retardation since birth and has required life-long custodial care. Under the BI model, a decision is made based solely on the medical information provided by the medical team.

In the absence of an appointed health care agent, most states will allow the family to proceed with health care decision-making under the SJ or BI models even in the absence of CCE. The family members who know the patient best?and hopefully have his best interest at heart?are allowed to make the necessary healthcare decisions. But this cannot be so in New York, where legal gridlock in Albany results in medical gridlock at the bedside. In New York, when there has been no appointment of a health care agent (and there is no CCE), third-party family members have no authority to speak for the patient. These distraught people can do little more than helplessly watch as the medical machine grinds through a patient’s final days, months, or even years. The only recourse might be a situation where the patient’s condition becomes so precarious that true medical futility may be recognized on the basis of inefficacy of treatment that is both a very high burden and a very low benefit for the patient.

In New York, the legislation (Family Health Care Decision Act) to correct this medical atrocity has been proposed annually for 13 years. There has been much opposition to this important piece of legislation for far too many years. Only last year, the Catholic Church softened its position and accepted a compromise on the abortion issue as represented in the bill’s language regarding the unborn child. The resultant language states ?. . . an incapacitated woman should . . . consider the impact of treatment decisions on the fetus.? Setting aside the obvious question as to what level of ?incapacity? a woman may have and yet still ?consider,? the phrase is useful as rewritten. If the pregnant woman has decisional capacity, she will most certainly give consideration to the baby she is carrying. If the pregnant woman does not have decisional
capacity in this tragic situation, then the loving family will give consideration to both the pregnant woman and the baby she is carrying. Any reasonable person would come to the same conclusion. Have we not kept pregnant women alive after a traumatic injury?ultimately leading to death?in order to maintain the pregnancy long enough to give the unborn child a viable chance of life? And yet, Assemblywoman Deborah Glick has trouble with this issue. Her concern is stated as being worry about the court?s interpretation of the bill?s language (particularly the reference to the fetus) relative to Roe v. Wade.

Another assemblyman, Daniel O?Donnell, is also displeased with language of the bill stating that decision-making rights should go to the ?close friend or relative? who is most familiar with the patient?s wishes. As a doctor at the bedside, this language points adequately to the most appropriate person. Even though the word ?spouse? is conspicuous in its absence, it is unnecessary. As an ethicist at the bedside, I have consulted on cases where the estranged spouse stepped aside in deference to the live-in companion. Assemblyman O?Donnell, as a gay man seeking to marry his partner, wants domestic partners on the same plane as spouses. I hold that the current language accomplishes this need without distinguishing between spouses and partners. Nevertheless, if needed, the New York State Surrogate List (spouse, adult child, parent, sibling, and close friend) can be easily inserted and even amended?if necessary?to include language referencing ?domestic partner.?

The city of Washington, D.C. was in the same predicament as New York and Missouri until the D.C. Health Care Decisions Act was passed in 2004. The long-standing D.C. Surrogate List was composed of spouse, adult child, parent, sibling, religious superior, and nearest living relative. The listing did not recognize a close friend, and it was blind to domestic arrangements. The amendment made three substantial changes: 1) included ?domestic partner,? 2) included ?close friend,? and 3) allowed for hierarchy flexibility in terms of recognizing a person of lower surrogate authority if there was clear evidence that this individual had knowledge of the patient?s wishes and desires.

Albany has been in gridlock regarding this issue for well over a decade. The legislators? refusal to successfully address this immense problem has broken families, stymied health care, and wasted health care dollars. In the language of ethics, passing the Family Health Care Decisions Act would be utilitarian?the greatest good for the greatest number of people. Legislators?such as Glick and O?Donnell?who seem to be blinded by their narrow and personal agendas, clearly lose the more appropriate global picture and its benefits for the larger populace.

References


