Many times in these columns, the issue of advance directives has been addressed and the contributors have repeatedly emphasized the importance of appointing a health care agent. Various national surveys have revealed that only about 20 - 30% of the population have taken the initiative to appoint someone to speak on their behalf when they are unable to do so.

Many reasons have been suggested for the failure to appoint a health care agent. Some reasons involve a frame of mind: reluctance, apathy, fear, and procrastination—even a kind of denial where death is something that happens to someone else. Some individuals, though, simply have no one that they can trust with such important issues. Other individuals simply refuse to bother members of the family with such concerns, failing to realize that the bother could be exponentially greater for the remaining family members because of a failure to address the issue in a timely manner.

Nationally prominent incidents, such as the case of Terry Schiavo, are useful at the societal level in that the importance of advance directives is brought to the forefront. In my ethics consultations with patients and their families, the mere mention of this woman and the beleaguered family underscores the importance of family consensus and makes for an easier conversation.

Ideally, careful consideration and discussion should lead to an end-of-life scenario where the health care agent faithfully carries out the medical directives of the patient. Nevertheless, in spite of the appropriateness of and need for the advance directive, it is not without difficulties. The primary clinical difficulties with the directive are the way that a health care agent is chosen and the manner in which that individual carries out the duties of being the agent. The latter of these situations can be particularly disturbing in that the health care agent may be making medical
decisions that are at variance with the known wishes of the patient. This type of scenario often creates considerable strife among family members. Given the gray zones of medicine, it should not come as a surprise that a patient’s best interest may be hard to delineate, and that it may be very difficult to remove the individual who was actually appointed as health care agent.

For example, in New York State the law grants the health care agent particularly broad powers, and the agent may only be removed from decision-making authority if he is not acting in the patient’s best interest. In addition, removal of the appointed agent may require a legal ruling: an ordeal that a family may not wish undertake during such a stressful time. Perhaps if the health care agent knows the patient’s prior wishes (an issue that should have been broached in the discussion of accepting the appointment) and chooses not to follow them, then the agent should consider recusing himself as the appointed agent. But this is a matter of ethics to which only the health care agent can attend.

The other situation, mentioned above, was that of choosing a health care agent. In many families, this process never occurs, and the patient may develop a medical condition requiring immediate hospitalization and intense care. If the patient has not made her wishes known in the past and cannot speak for herself now, then none of the members of the family have any distinct prior knowledge of any preferences regarding medical decisions.

There is always a possibility, though, that a patient will regain consciousness and recover a measure of decisional capacity, and appoint a specific individual as her health care agent. The appointment of a health care agent is felt to require only a low level of decisional capacity (as compared with the decision to undergo organ transplantation, which normally would require a very high level of such capacity). Consequently, this appointment is accomplished with relative ease. The patient need only to understand and to identify the proposed health care agent, and the agent need only accept the responsibility. When this happens in New York, the doctor is now obligated to follow the directive of the newly-appointed health care agent, who possibly may have no prior knowledge of the patient’s end-of-life medical desires.

This is a curious ethical dilemma for the medical team and the ethicist. Prior to the appointment, the medical team was making medical decisions on the basis of benefits and burdens, efficacy, and medical appropriateness all from a medical perspective. After the appointment, the team is now following the directives of an individual who is operating (at best) from a substituted judgment perspective, and (at worst) from a best interest level. The law grants authority to the health care agent, but does not require knowledge. The ethics literature is starting to emphasize the dichotomy of the agent making a decision that the patient would have made (substituted judgment) as juxtaposed against a decision that the agent alleges that the patient might choose on a purely medical basis (best interest). This is a very important differentiation, and in allowing the hegemony of the health care agent, the distinction may become blurred.

Even in recognizing the above problems, I strongly suggest that anyone without an advance directive should remedy the situation. Joint decision-making is the current medical-legal standard. Medical decisions between the patient, the family, and the doctor are often made at the bedside as a medical crisis unfolds. Advance directive decisions between the patient and the family should be made at the fireside in the comfort of one’s home before a medical crisis develops. Even though potential difficulties exist, the advance directive is the best way to
memorialize your end-of-life medical preferences.

Additional Resources

- Free Advance Directive Form (with instructions) (PDF)

Podcast Episode:

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