

MEDICAL DECISION MAKING FOR PATIENTS LACKING AN ADEQUATE SURROGATE¹ **DECISION MAKER**

Executive Summary

When patients with limited or no decisional capacity lack a surrogate and need to make a significant medical decision, caregivers should consider calling for an ethics consultation in addition to seeking opinions from Partners Office of General Counsel or BWH Risk Management as an alternative to seeking a court appointed guardian. The goal of the consultation process is to reach consensus about the most appropriate course of action. The chosen course should be made based on an estimate of what the patient would be likely to choose based on evidence concerning his or her values from among the medically available options.

Background

Over the past three decades, medical decision-making has become progressively more patient-centered. As a result, it is now standard practice to involve patients thoroughly in their treatment decisions. Many medical decisions have a strong qualitative or subjective component so that equally informed patients make different choices based on their personal values. However, a patient's decisional capacity may be limited by decline in cognitive function (e.g. Alzheimer's disease) or by the circumstances of serious illness (e.g. delirium). In these instances it becomes necessary to rely on a surrogate decision maker for a substituted judgment.¹ (see VIII-13, Policy on Patients with Limited Decision Making Capacity).

With the advent of advance directives such as the Massachusetts Health Care Proxy, patients can identify and document a person to act as their health care agent in the event the patient loses decisional capacity. In those circumstances, the agent has the same legal authority as the patient with respect to health care decisions. In the absence of a Health Care Proxy, the patient's next of kin serves as a surrogate. It is standard medical practice to counsel the health care agent or surrogate to make a decision based on what he or she believes the patient would choose because it is knowledge of the patient and his or her preferences which gives the agent or surrogate the moral and legal authority to decide on the patient's behalf.

When there is no clearly identified surrogate, this approach to patient-centered decision making will not work. Another valid legal and ethical standard for medical decision making is based on what is in the patient's best interest from a purely objective, medical perspective (e.g. gives the best chance of survival, the least pain and suffering, and what most people would choose in such a circumstance). Combining this knowledge with any available information about the patient "as a person" is the ideal way to make a patient-centered decision when there is no surrogate. The following process, implemented by an ethics consultation, is designed to gain such a perspective.

PROCESS

¹ Surrogate is a general term meaning "substitute". In this setting it refers either to someone designated by a health care proxy document or the next of kin. Only surrogates can make a substituted judgment. When there is no surrogate medical decisions should be based on the patient's "best interest". This policy describes the elements of a "best interest" decision that incorporates specific details concerning an individual patient.

1. Thorough investigation of the patient's background should be undertaken. Living arrangements, friends, community involvement, religious affiliation, prior health care decisions and discussion with previous care providers gives a sense of the patient's life story and medical priorities. The patient's primary care physician should always be contacted in this regard.
2. The patient's current response to his/her illness and treatment should be assessed: freedom from pain, outlook, and satisfaction with treatment already initiated.
3. Statements the patient previously made regarding medical treatments should be taken into account, especially concerning interventions that are relevant to the patient's current situation (e.g., ventilators, nursing homes, feeding tubes, ostomies, etc.)
4. All available treatment options should be considered. These can be offered by any current caregivers: attending physicians, consultants, house staff, nurses, social workers, etc.

The goal of this process is to reach a synthetic (as opposed to a substituted) judgment of what the patient would probably choose or want. This should not represent the judgment of a single caregiver but should be a consensus of what a group of people from multiple disciplines directly connected with the patient's care believe that the patient would be likely to choose. If, following this process, there is no consensus on a care plan and the options include invasive treatment or withholding life-sustaining treatment, consultation with the Office of General Counsel is necessary to determine whether a court-appointed guardian should be obtained.

SPECIAL SURROGATE CATEGORIES

1. Limited Surrogate. In this circumstance there is no legal representative (assigned healthcare agent, next of kin or legal guardian) but there are friends, neighbors, or more distant relatives who no longer play an active role in the patient's life but want to be helpful. These people can provide useful information about the patient's beliefs and values and their information may assist caregivers in thinking about what the patient would choose. Input from limited surrogates should be integrated with medical information concerning prognosis, treatment options and likely outcomes.
2. Impaired Surrogate. Family members are in a position to play a role in medical decision making but they may be unable or unwilling to fully participate. Alternatively, they may be impaired by virtue of physical distance, emotional or psychological incapacity or evidence that the patient would not want them as a surrogate. When this is the case, the caregivers should attempt to integrate relevant information provided by the impaired surrogate, but must ultimately make decisions based on a shared perspective about what is in the patient's best interest.
3. Multiple Conflicting (Potential) Surrogates. Several family members of equal kinship may want to be surrogates, but they may disagree or have limited knowledge of the patient's wishes. If possible, it is best to identify one person to act as the surrogate, document that person's role and notify the other family members. Factors that would favor someone as surrogate include: closeness to and knowledge of the patient, concern for the patient's welfare, evidence of responsible decisional capacity in other settings and availability for emergency decisions. If family members resist the designation made by the care providers of the person to act as surrogate, it may be necessary to seek a court appointed guardian.

This policy describes a process, implemented by an ethics consultation, for making medical decisions for decisionally incapacitated patients. The ideal process will integrate the medical facts of the case with knowledge of the patient's values, to reach a treatment decision that is most likely to represent the

patient's choice. This process will help caregivers reach a more timely and objective decision and can often avoid the need for a court appointed guardian.

SPONSOR: Anthony Whittemore, M.D.

APPROVED: Medical Staff Executive Committee, **12/05**
Senior Management Group, **12/05**
Care Improvement Council, **12/05**