

# Making Treatment Decisions for Incapacitated Older Adults Without Advance Directives

*AGS Ethics Committee*

## BACKGROUND

Geriatric practitioners are often faced with the problem of making treatment decisions for patients who lack decisional capacity. AGS has long encouraged the use of oral and written advance directives, or the participation of traditional surrogates, such as close family members, to aid in this process. However, many older patients who lack decisional capacity have neither executed an advance directive nor previously discussed their preferences regarding medical treatments. Even when there are traditional surrogates, there may be disagreement among parties, legal or regulatory obstacles, or other problems that impede decision-making.

## POSITION 1

Except in cases of obvious and complete incapacity, an attempt should always be made to ascertain the patient's ability to participate in the decision-making process.

### *Rationale*

Respect for autonomous decision-making is a fundamental ethical principle that should be adhered to whenever possible.

Decisional capacity is specific to each patient and to each medical decision. Patients with mild cognitive impairment may still have decisional capacity for some choices, including the ability to designate a surrogate decision-maker. Furthermore, those who cannot comprehend complex situations may still possess the capacity to make simple decisions or to convey their opinions regarding the burdens and benefits of ongoing treatments.

## POSITION 2

It should not be assumed that the absence of traditional surrogates (next-of-kin) means the patient lacks an appropriate surrogate decision-maker. A nontraditional surrogate, such as a close friend, a live-in companion who is not married to the patient, a neighbor, a close member of the clergy, or others who know the patient well, may, in individual cases, be the appropriate surrogate. Health professionals should make a conscientious effort to identify such individuals.

### *Rationale*

The most appropriate surrogate for the incapacitated patient is one who has loving and intimate knowledge of the

patient's wishes or value systems. In some cases, surviving family members have only remote knowledge of the patient's values, or are estranged, whereas close friends or others might better represent the patient's most fully developed value system. If such a patient has developed other intimate relationships, there may well be an identifiable and appropriate surrogate.

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## POSITION 3

After a conscientious effort has failed to identify an appropriate surrogate, a group of individuals who care for the patient may determine appropriate treatment goals and design a humane care plan to meet those goals. This group might consist of a multidisciplinary healthcare team, including physician, nurse, nurse's aide, clergy, and others who have worked most closely with the patient. If an institutional ethics committee has been established to aid in decision-making, the above mentioned individuals or their representatives should participate in any proceedings.

The standard of decision-making regarding treatment should consider any present indications of benefits and burdens that the patient can convey and should be based on any knowledge of the patient's prior articulations, cultural beliefs if they are known, or an assessment of how a reasonable person within the patient's community would weigh the available options.

For some particularly difficult cases, e.g., those involving especially vulnerable individuals, or where motives might be in conflict, external advice or review should be considered.

### *Rationale*

There are patients whose backgrounds are completely unknown, or who have never had decisional capacity and whose values would be unknown. For such individuals, a community of health care providers has often come to know the patient best and is best situated to understand how to advance the patient's best interests.

## POSITION 4

Patients with long-term incapacity and no surrogate available are best served by having a continuous surrogate. The broader community should ensure that an appropriate guardian is appointed or that other decision-making procedures are followed, as established by laws of each state.

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**Rationale**

There are many incapacitated patients, such as those in long-term care institutions, for whom decisions about health care will be recurrent over their remaining lifetime.

**POSITION 5**

For urgent, life-threatening situations, such as imminent cardiopulmonary arrest, health care providers and institutions should develop methods to make decisions for incapacitated persons without surrogates. These methods might include allowing the attending physician and a consulting physician to make certain choices within established protocols subject to retrospective review.

**Rationale**

Resuscitation of patients with serious underlying illness is associated with a poor outcome.<sup>1-3</sup> Although physiological resuscitation can sometimes be achieved, function is not restored or may worsen despite resuscitation, consigning the patient to a lingering death on artificial life support. Patients should not be forced to receive inappropriate treatment because they lack a surrogate decision-maker.

**POSITION 6**

In order to mediate situations when surrogates have been identified but disagree, or when surrogates with uncertain legal standing emerge, or when traditional and nontraditional surrogates disagree, institutions should establish mechanisms for intra-institutional conflict resolution, such as an ethics committee. Court proceedings should be a last resort.

**Rationale**

Most apparent conflicts are resolved within a few days.<sup>3,4</sup> Institutional conflict-resolving mechanisms that seek to enhance dialogue and communication can speed and facilitate this process. In contrast, court proceedings are divisive, expensive, and time-consuming.

**POSITION 7**

Surrogate decision-making laws and policies should not hinder the patient's ability to die naturally and comfortably. Evidence from competent patients in similar circumstances should shape the plan of care for an individual patient in the absence of evidence that the patient would want otherwise. This principle should apply in all settings, including hospital, nursing home, and the home.

**Rationale**

Although the courts often presume in favor of life prolongation in the absence of a clear advance expression to the contrary, there is ample evidence that most people would prefer a natural death to prolongation of dying by artificial means.<sup>4-8</sup> There is no evidence that the majority of people would prefer prolonged or painful dying.

**POSITION 8**

Rigid criteria such as having a specific disease, time-limited prognosis, or specific degree of impairment (persistent vegetative state; "permanent unconsciousness"), or being placed in a poorly defined category ("terminal condition," "imminent death"), are inadequate alone to determine whether a surrogate should have the authority to refuse life-sustaining treatment for a patient.

**Rationale**

There is often substantial uncertainty about prognosis and the effects of treatment in serious illness.<sup>9-11</sup> Most patients' preferences for life-sustaining treatments are based more on projected quality of life rather than length of life.<sup>12-14</sup>

**POSITION 9**

In jurisdictions where laws and regulations are cumbersome, impractical, or do not advance the widespread preferences for natural and comfortable dying, health professionals should work to educate legislators as to the need for change in these laws. Laws should be based on needs and interests of the patient as he or she might have defined them, not as the physician, the institution, or the state would define them.

**Rationale**

Existing laws and pending legislation governing surrogate decision-making are not uniform and are often unclear. There are differences among jurisdictions as to the extent of the surrogate's authority, the authority of nonfamily members, the permissibility of the patient's physician to act as a surrogate in certain circumstances, the degree of illness or disability that a patient must have in order for the surrogate to make decisions regarding life-sustaining treatment, and what means are to be used when limits are placed on specific surrogates.

In addition, some jurisdictions require "clear and convincing evidence" of the patient's previously expressed wishes, a standard that might be interpreted to require such compelling evidence that it is of little practical use. Decision-making standards that depend on knowledge of the patient's wishes, whether clearly known or merely presumed, will be insufficient for patients who lack both an advance directive and a surrogate decision-maker, or who have never had decisional capacity, such as those with severe mental retardation.

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