

IN THE FLORIDA SUPREME COURT

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IN RE: GUARDIANSHIP OF  
ESTELLE M. BROWNING,  
Incompetent

STATE OF FLORIDA and  
SUNSET POINT NURSING CENTER,  
Petitioners, Appellees

v.

DORIS F. HERBERT, as  
the Guardian on behalf of  
Estelle M. Browning,  
Incompetent,  
Respondent, Appellant

Case No. 74-174  
2d DCA #88-02887  
Pinellas Probate Div.  
#87-1176-6D-3

BRIEF OF THE AMERICAN GERIATRICS SOCIETY  
AS AMICUS CURIAE IN SUPPORT OF RESPONDENT

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Issue Presented for Review -

WHETHER THE GUARDIAN OF A PATIENT WHO IS INCOMPETENT BUT NOT IN A PERMANENT VEGETATIVE STATE AND WHO SUFFERS FROM **AN** INCURABLE, BUT NOT TERMINAL CONDITION, MAY EXERCISE THE PATIENT'S RIGHT OF SELF-DETERMINATION TO FOREGO SUSTENANCE PROVIDED ARTIFICIALLY BY A NASOGASTRIC TUBE?<sup>1</sup>

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<sup>1</sup> In re Guardianship of Estelle M. Browning, 14 FLW 956 (Fla 1989) at 962.

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EST OF E AMICUS

The American Geriatrics Society (AGS) is an organization of physicians and related professional health care providers whose special concern is with the health care needs of elderly persons. The AGS was founded in 1942 and now has approximately 5,300 dues-paying members. The AGS sponsors conferences and seminars, provides for collegial information-sharing, publishes a pre-eminent professional journal (The Journal of the American Geriatrics Society), and encourages improved health care services for elderly persons and research upon the illnesses from which they suffer.

The American Geriatrics Society and its members have had a long tradition of concern about the establishment of standards regarding the care of ill or dependent elderly persons. The AGS has tried to assure that even those elderly persons with severe dependency and limited personal and community resources gain access to the best possible health services. To that end, high priority has been given to encouraging care providers, the elderly, and their families to adopt an optimistic and energetic approach to treatment of illness. The AGS has written an amicus brief once before, in the Conroy case in New Jersey.<sup>2</sup>

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<sup>2</sup> Lynn, In the Matter of Claire C. Conroy, Amicus brief, 32 J Am Geriatrics Soc 915 (1984).

In the AGS Position Statement regarding Medical Treatment Decisions Concerning Elderly Persons,<sup>3</sup> the AGS affirms 1) a strong commitment to personal autonomy of patients; 2) both an appreciation of the beneficial potential of modern medicine and honesty regarding its side effects and limitations; 3) an affirmation of the inestimable value of life; and 4) a clear recognition of the inevitability of death.

According to the AGS Position Statement,

Patients' interests are not always best served by applying all theoretically beneficial treatments. Instead, the choice made should reflect that patients often have legitimate concerns about avoiding suffering, advancing their occupational or family concerns, mitigating disability, and sustaining independence. Particular medical interventions may not be warranted in light of overall effects on well being, although they may be expected to help a particular medical condition.

When patients cannot be informed or cannot reason about the available options in light of their own preferences and goals, the physician should, for any important decision or ambiguous choice, involve someone who knows the patient and can represent the patient's wishes in making the choice.

Caregiving professionals and institutions should make available to patients a full range of options for treatment, including the option of supportive care for dying patients.<sup>4</sup>

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<sup>3</sup> The American Geriatrics Society, Position Statement: Medical Treatment Decisions Concerning Elderly Persons, (May 1987).

<sup>4</sup> Id.

SUMMARY OF FACTS AND PROCEDURAL HISTORY

Mrs. Estelle Browning is 89 years old. Prior to a massive stroke on November 9, 1986, she was living an independent and enjoyable life, residing with her cousin, Mrs. Doris Herbert, who is now her legal guardian. She was active in her church and had a community of friends in the neighborhood where she lived for the past twenty years.<sup>5</sup> Her family physician, Dr. Lois West, described her as having experienced generally good health, with hypertension being the only significant medical condition for which she received treatment.<sup>6</sup>

Mrs. Browning had made two living wills. The first was witnessed by Mrs. Herbert and a friend after the death of Mrs. Browning's husband in 1978. Mrs. Browning destroyed this living will and completed a second after she was counseled to do so because Mrs. Herbert was a relative and the friend had since died. Mrs. Browning's new living will was signed on November 19, 1985 and witnessed by close friends and neighbors of twenty years. They testified to

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<sup>5</sup> In re Guardianship of Estelle M. Browning, Civil Case No. 87-1176-GE (Pinellas County Ct. Sept. 30, 1988) (testimony of Mrs. Rose Kings, paraphrasing Mrs. Browning) at 9.

<sup>6</sup> Id. (Testimony of Dr. Lois West) at 15.



Mrs. Browning's relief at having signed the living will and her belief that it would allow her to "go in peace when my time comes."<sup>7</sup>

In her living will, Mrs. Browning specifically indicated that she did not desire nutrition and hydration to be provided by gastric tube or intravenously if her condition was one covered by the living will. Mrs. Browning's family physician testified that she (the physician) was given the living will by Mrs. Browning and that she probably discussed it with Mrs. Browning as she customarily did with her patients.<sup>8</sup> The physician believed that Mrs. Browning meant to preclude long term persistence in a severely disabled state prior to death.<sup>9</sup>

Mrs. Browning's present condition is described as irreversible but not terminal, since she might live for many months. The stroke she suffered involved a large hemorrhage in the left parietal region of her brain. Although Mrs. Browning received extensive treatment, the damage to her brain was clearly major, permanent, and irreversible. Hospital records from the time shortly after the stroke reflect that Mrs. Browning was totally unresponsive except that she would respond to deep pain by moving. Because she was unable to swallow, a gastrostomy was performed on

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<sup>7</sup> Id. (Testimony of Mrs. Rose King) at 9.

<sup>8</sup> Id. (Testimony of Dr. Lois West) at 15-16.

<sup>9</sup> Id. (Testimony of Dr. Lois West) at 17.

November 20, 1986. On November 21, 1986, Mrs. Browning was transferred to Sunset Point Nursing Center. In the months that followed, Mrs. Browning's medical records reflect frequent problems with nausea, bed sores, and other unpleasant chronic maladies. In May, 1988, the gastrostomy tube became dislodged. Since that time, Mrs. Browning has been fed through a nasogastric tube.<sup>10</sup> At the time of the September 1988 hearing, Dr. Avery, her physician at the nursing home, described her condition as follows:

Mrs. Browning has been in a stable but poor condition over the last few months. She has not been able to feed, care or do any activities and is totally bedridden. Her mental status is poor and she dose [sic] not respond to verbal stimuli at all. She dose [sic] respond with primitive movements to tactile or painful stimuli. She does not appear to interact with her environment apart from the above. Her physical condition is stable and her large decubitus ulcer has remained stable because of good nursing care.<sup>11</sup>

At the initial hearing, one nurse caregiver gave conflicting information indicating that Mrs. Browning is much more capable of interactions with the environment, including some speech.<sup>12</sup>

On September 2, 1988, nearly two years after Mrs. Browning's stroke, Mrs. Herbert, her guardian, filed a

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<sup>10</sup> In re Guardianship of Estelle M. Brownins, 14 FLW 956 (Fla, 1989) at 962.

<sup>11</sup> Id. at 956.

<sup>12</sup> In re Browning, Civil Case No. 87-1176-GE, Pinellas County Ct. Sept. 30, 1988) at 38.

petition to withdraw the nasogastric tube. This petition was denied on October 11, 1988 by Judge Penick, County Court, Sixth Judicial Circuit Pinellas County, Florida. Mrs. Browning's guardian appealed the order of the trial court denying her petition to terminate artificial life support. Judges Altenbernd, Ryder and Parker in the District Court of Appeal of Florida, Second District, held on April 10, 1989 that Mrs. Browning's guardian is entitled to make the decision to terminate artificial life support. Because this decision expressly construes a provision of the state constitution and involves issues of great public importance, the Appeal's court certified the following question to the Florida Supreme Court:

WHETHER THE GUARDIAN OF A PATIENT WHO IS INCOMPETENT BUT NOT IN A PERMANENT VEGETATIVE STATE AND WHO SUFFERS FROM AN INCURABLE, BUT NOT TERMINAL CONDITION, MAY EXERCISE THE PATIENT'S RIGHT OF SELF-DETERMINATION TO FOREGO SUSTENANCE PROVIDED ARTIFICIALLY BY A NASOGASTRIC

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The Supreme Court's answer to this question will directly affect the health care decisions of millions of elderly patients. The condition of Mrs. Browning is exceedingly common. Nearly a quarter of all adults will suffer a progressive dementing disorder prior to death.<sup>14</sup>

13 In re Guardianship of Estelle M. Browning, 14 FLW 956 (Fla 1989) at 962.

14. Cohen and Eisdorfer, Dementing Disorders, The Practice of Geriatrics, (Calkins, Davis, and Ford, eds, 1986), at 194.

The vast majority of Americans will have a time in their lives when they do not have the capacity to make health care decisions, either because of illness or advanced age. The American Geriatric Society respectfully submits the following argument in the hope that it will assist the Court in establishing sensitive, appropriate, and ethically justified decision-making procedures for cases involving incompetent persons.

#### SUMMARY OF ARGUMENT

The American Geriatrics Society calls upon the Supreme Court of the State of Florida to endorse three key substantive claims. First, that health care should aim to provide for each patient the best possible future, and, whenever possible, that the patient should define what is best. Second, that the full range of alternatives that competent patients are allowed to pursue should be available for incompetent patients. Third, that alternatives which are in fact best for a patient should not be barred to that patient because of the patient's status as being not "imminently terminal," as residing in a nursing home, as having family with conflicts of interest, or for any other reason arising from the patient's current circumstances.

Additional procedural safeguards are always also barriers to timely and private decision-making and these countervailing considerations must be weighed carefully in

establishing new requirements. Thus, the Court should be careful to draw any new procedures quite narrowly and to specify whether they are required or recommended.

The Supreme Court of Florida was not asked to rule on whether Mrs. Browning should have artificial tube feeding. Indeed, although the question before the court is momentous, it is essentially conceptual and straightforward. The answer should be that a guardian of an incompetent patient (of any sort, including one who is "not in a permanent vegetative state and who suffers from an incurable, but not terminal condition")<sup>15</sup> should be able to choose a course of care that includes foregoing "sustenance provided artificially by a nasogastric tube"<sup>16</sup> when that choice advances the patient's interest. Further, the definition of the patient's interests should be the patient's own whenever possible. If the patient has left enough evidence as to what he or she would want done and that course would be available to a competent patient, then that should be the choice effectuated.

#### ARGUMENT

- I. OPTIMAL MEDICAL DECISIONS ARE THOSE WHICH ADVANCE THE WELL-BEING OF INDIVIDUAL PATIENTS AS DEFINED BY EACH PATIENT'S VALUES AND PREFERENCES.

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15. In re Guardianship of Estelle M. Browning, 14 F.L.W, 956 (Fla 1989) at 962.

16. Ibid.

All medical decision-making aims at benefitting the patient as much as possible. Health care professionals take as their task the discernment, in so far as possible, of the potential futures of each patient. With the health care professional's help, the patient must choose from among various options concerning how his or her life can be lived. Different courses of care often will offer futures that differ in important ways: e.g., in degree of suffering and pain, the degree of responsiveness to others, and the risk of hastened death. An evaluation from the patient's perspective of the relative desirability of the various potential treatment options should be the central concern.<sup>17</sup>

Each of us will value these various possible outcomes somewhat differently depending on our own experiences and values. People have a number of goals, values, and concerns and hold disparate views on the meanings of their own lives. When various desirable elements combine in such a way that one goal can be advanced only at the expense of another, different people will choose differently. For example, when a medication can be given for pain that also risks hastening death, individuals will choose according to their unique

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<sup>17</sup> See, e.g., President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Making Health Care Decisions (1982); and The Hastings Center, Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, Indiana University Press, Bloomington, Indiana (1987).

aversion to pain or desire to defer the time of death. Although for most people at most times, the prolongation of life is a very important objective, sometimes the conditions that are necessary in order to prolong life are too burdensome to the patient for the endeavor to be worthwhile. Deciding to forego a life-sustaining treatment is, of course, a serious undertaking that calls for caution and prudent deliberation. But it is, finally, a decision that nearly all people would make in some circumstances. At the extreme, for example, some combination of suffering, short survival, and family burden would justify, for nearly anyone, foregoing a very painful treatment which probably would prolong life, though only for a brief period.

11. THE FULL RANGE OF TREATMENT ALTERNATIVES AVAILABLE TO COMPETENT PATIENTS SHOULD BE AVAILABLE TO INCOMPETENT ONES.

Competent persons in this society are allowed to choose among various goals and objectives with a wide range of freedom. Only if there is substantial harm to others (and especially if the others are dependent upon the person causing harm or are otherwise defenseless) are competent people legitimately barred from certain behaviors. This concern over harm to others is the core of what have been called "state interests" in decisions to forego life-sustaining treatment. While these state interests merit thoughtful consideration by the state, they have rarely been

held to be sufficient to require sustaining the life of a patient who is not well-served by continued life, or who refuses the treatment.

In health care, the competent person may decline any treatment<sup>18</sup> except in the unusual case when doing so creates a public health hazard,<sup>19</sup> or violates a compelling obligation engendered by the patient's status (e.g., prisoners may have to stay alive for punishment<sup>20</sup> and parents may be - though they rarely are - required to save their lives in order to raise their children)<sup>21</sup>. Thus, a competent Jehovah's Witness afflicted with aplastic anemia or a persistently bleeding gastric ulcer may choose to remain faithful to a religious prohibition on taking blood, and therefore to refuse life-saving transfusions.<sup>22</sup> Both the government and the professional caregivers are barred from imposing life-saving treatment on such a patient.

When deficits in understanding, communication, or reasoning make a patient unable to be responsible for his or

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<sup>18</sup> See, e.g., President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, Deciding to Forego Life-Sustaining Treatment (1983).

<sup>19</sup> See, e.g., Jacobson v. Massachusetts, 197 U.S. 11 (1905).

<sup>20</sup> Commissioner of Correction v. Myers, 379 Mass. 255, 399 N.E. 2d 452 (1979), but see Zant v. Prevatte, 248 Ga. 832, 286 S.E. 2d 715 (1982).

<sup>21</sup> See, e.g., Jefferson v. Griffin Spalding City Hospital, 247 Ga 86, 274 S.E.2d 457 (1981).

<sup>22</sup> In re Osborne, 294 A.2d 372 (D.C. 1972).



her own decisions (whether determined to be incompetent by a court or not), surrogate decision-makers should proceed carefully and with due consideration. They will have to examine the situation, its likely outcome untreated, and the effects of all available plans of care. The surrogate must consider whether what is known of this patient's goals, concerns, and values leads to an individualized assessment of the merits of different choices. In the absence of any evidence to the contrary, the surrogate can reasonably presume that the patient would want to pursue such outcomes as these: cure, relief or prevention of disability, comfort and symptom control, enhanced capacity for human relationships, restoration of competence and control, the opportunity to complete important tasks, amelioration of detrimental effects on loved ones, and delay of death.

The task of appropriately weighing these general and individual goals is complex. When a substantial difference in the length of life hangs in the balance, the choice should be afforded serious deliberation. Decision-makers must accept this burden and try to balance the various considerations in making the best possible choice. To simplify the endeavor by adopting one ordering and weighting of goals for all patients would ignore the diversity of value commitments among people, an outcome that is to be disdained in a society that values freedom and pluralism.

When the person cannot choose for himself or herself, it is doubly important that surrogates be protective of the patient's life and reluctant to allow it to be foreshortened. However, hesitance and caution does not lead inevitably to a sweeping refusal to allow death to occur. There are some conditions that entail such substantial suffering and isolation from loved ones that treatment to prolong such a life should not be required.<sup>23</sup> If it were, the decision-making incapacity itself would become the barrier to the morally correct withdrawal of treatment that had become unwarranted and harmful. Prolonging such distress can not only be cruel to the patient but also distressing to family and friends and dehumanizing to care givers.

Important issues when surrogates make decisions include deciding who should serve as a surrogate and what standard should be used for determining the patient's wishes. Because it is the patient's values and preferences which guide the determination of well-being, the surrogate should be someone who can best articulate the patient's values. Family and friends are usually in the best position to speak on behalf of the patient since they not only know the patient's biography but are a part of it. Their relationship with the patient, and their commitment to care for and about him or

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<sup>23</sup> President's Commission, Deciding to Forego Life-Sustaining Treatment, 3 passim; See also Rosner, "Prolonging the Act of Dying," 31 *J. Am. Geriatrics. Soc.* 382 (1983), and Hastings Center, Guidelines, passim.

her, precedes their role as surrogate. Not only are they more likely than others to have conversed with the patient concerning issues of foregoing treatment, but they are familiar with the patient's values and preferences through other life choices. The knowledge that close friends and family have about a loved one which is acquired through shared life experiences is of very great value.

The role of family and friends must not be reduced to that of a tape recorder which can report past conversations concerning life-sustaining treatment decisions. Of course, vulnerable patients must be protected from harm they might suffer at the hands of a guardian who has an unacceptable conflict of interest, one which prevents him or her from acting in good faith to promote the well-being of the patient. But every close family member or friend inevitably will have some conflict of interest, since out of the very nature of the relationship they are the likely ones to feel the patient's suffering, to inherit the patient's estate, or be the most distraught at the patient's earlier death. It is not conflict of interest itself that should be avoided, but overwhelming conflict that precludes good faith in decision-making. Family and friends must ordinarily be allowed to give voice to their own view of the patient's values and preferences, even if there was no explicit statement on the issue from the patient. Such a perspective should be granted substantial weight in the decision making.

What should count as sufficient evidence of a patient's preference to sway decision-making is an important issue. The clearest evidence of patient preference is some type of advance directive such as a living will or a durable power of attorney. Evidence is obviously more weighty when it shows a strength and durability of belief such that a change of heart would be unlikely. Decisions to forego a substantial life extension should not be based on remarks that were remote, general, spontaneous, and made in casual circumstances. As noted in the Conroy case, evidence used to make a serious decision should not include "an off-hand remark about not wanting to live under certain circumstances made by a person when young and in the peak of health" and "informally expressed reactions to other people's medical condition and treatment."<sup>24</sup>

Most of the patients served by the members of the AGS are persons who have long life histories. Over many decades they have made choices, developed preferences, made religious and other value commitments, and been substantially in control of the course of their lives. AGS members have been in the forefront of efforts to recognize and respect this

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24. In re Conroy, 98 N.J. 321, 486 A.2d 1209 (1985)

fact and have worked to ameliorate the common age-based abrogation of a person's authority to continue to direct the course of his or her life.<sup>25</sup>

This commitment extends to protecting the authority of the patient to make choices concerning future medical care if decision-making capacity should become impaired. When patients have not given explicit direction in advance but have lived lives that provide adequate evidence of their own preferences, these should be decisive when multiple alternative care plans are possible. And, if the patient has left no credible evidence as to how he or she would view the situation, then the choice must be made as the "usual" patient in such a circumstance would choose, and certainly the usual patient would choose to forego some kinds of life-extending treatment.

111. NO CLASS OF POTENTIALLY AFFECTED PATIENTS SHOULD BE CATEGORICALLY EXCLUDED FROM THE EVALUATION OF THE MERITS OF FOREGOING ANY TREATMENT, INCLUDING THAT INTENDED TO IMPROVE NUTRITION AND HYDRATION.

In order to simplify difficult decisions to forego life-sustaining medical treatment, many argue for the categorical exclusion of particular plans of care like foregoing artificial hydration and nutrition, at least for particular kinds of patients like those who are not terminal or not involve "imminently" dying. Such an approach violates the central goal of medicine: to promote the well-being of

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25. See, e.g., Butler, Why Survive? Being Old in America. (Harper & Row, New York, 1975).

patients according to each patient's values and preferences to the best that these can be determined.

In the past few decades, medical science has developed a large number of interventions that can extend patients' lives. However, often patients are not thereby restored to full and vibrant health. Instead, the time gained is marked by ill health or disability. The physician's obligation to the patient is to collaborate in optimally utilizing the available interventions, neither giving up when much of value could yet be achieved nor forging ahead into life-extending treatments whose detrimental aspects ensure that they are neither desired by the patient nor, on balance, useful.<sup>26</sup>

This balancing of benefits and burdens is as true of rather common and minor interventions such as antibiotics, physical therapy, and laboratory blood tests as it is of more dramatic and mechanical interventions such as artificial respiration by a respirator or dialysis for kidney failure. Of course, the common and minor interventions ordinarily have fewer substantial untoward effects and thereby are more commonly appropriate to use. However, any treatment has unwanted side-effects that may at times dictate foregoing

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<sup>26</sup> See, e.g., Besdine, Decisions to Withhold Treatment from Nursing Home Residents, 31 J.Am.Geriatrics Society, 62 (1983) President's Commission, Deciding to Forego Life-Sustaining Treatment (1983); and Hastings Center, Guidelines (1987).

that treatment.<sup>27</sup> Such a decision should be based on the promotion of the well-being of the patient according to his or her own values and preferences.

This principle applies as well to the treatments now available for patients who cannot eat in the usual way, including for example, providing a liquid diet through a tube from the nose to the stomach (nasogastric) or through the abdominal wall to the stomach (gastrostomy), providing soluble nutrients and liquids into a vein or muscle in the arm or leg (intravenous fluid therapy), or providing a balanced chemical diet into a large vein in the chest (parenteral hyperalimentation).

Each of these procedures must be done by or on the authority of a physician and each entails some risks and harms. For example, nasogastric tube feedings commonly cause annoyance and discomfort that can require restraints, as well as a substantial risk of sinus and lung infections of bleeding from the esophagus or stomach, and of diarrhea. Gastrostomy feedings require surgical placement of the tube, with associated risks. The intravenous routes, when used to provide balanced nutrition, cause frequent and serious ill-effects such as metabolic abnormalities and fluid overload. Any of these procedures commonly entail increased monitoring

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<sup>27</sup> See, e.g., Steel, Gertmen, Crescenzi, and Panderson, Iatrogenic Illness on a General Medicine Service at a University Hospital, 304 N Engl J Med 638 (1981). See also, Hastings Center, Guidelines (1987).

of blood chemistry and urine output, which themselves incur risks.<sup>28</sup> Whether such treatment is justified requires the same kind of assessment as for any other treatment.

For the vast majority of patients, medical provision of nutrition and hydration offers substantial benefits that clearly overcome the burdens imposed by the treatment offered. However, for some patients, the treatment is not justified because it does not offer a reasonable expectation of improving the patient's well-being as seen by the patient.

Most people imagine dehydration and malnutrition to be uniformly anguishing. However, severely ill or dying people do not ordinarily experience any discernable distressing symptoms. Competent dying patients sometimes take in no food or water and yet do not feel hungry or thirsty<sup>29</sup> In such

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<sup>28</sup> See, e.g., Canizaro, Methods of Nutritional Support in the Surgical Patient, in Surgical Nutrition, 13 (Yarborough ed. 1981); Silberman and Eisenberg, Parenteral and Enteral Nutrition for the Hospitalized Patient (1982); Michel, Serrano, Malt, Nutritional Support of Hospitalized Patients, 304 N.Engl J Med. 1147 (1981); Faintauch and Deitel, Complications of Intravenous Hyperalimentation: Technical and Metabolic Aspects, in Nutrition in Clinical Surgery, Dietel ed, (1980).

<sup>29</sup> See, e.g., Schmitz and O'Brien, Observations on Nutrition and Hydration in Dying Cancer Patients in BY No Extraordinary Means (J.Lynn, ed., 1986); Cox, Is Dehydration Painful?, 9 Ethics and Medics 1-2 (1987); Baines, Control of Other Symptoms, in The Manasement of Terminal Disease (Saunders, ed., 1978); Crowther, Management of Other Common Symptoms of the Terminally Ill, in The Dying Patient (Wilkes, ed., 1982). See also Bouvia v. County of Riverside, No. 159780 (Cal.Super.Ct, Riverside County) (1983) (declaration of Charles Paul Rosenbaum, M.D., Brophy v. New England Sinai Hospital, 398 Mass. 626, 631 n.20, 497 N.E. 2d 626, 631 n.20 (1986); In re Grant, 109 Wash. 2d 545, 747 P.2d 445, 453



circumstances, the correction of laboratory evidence of malnutrition and dehydration might well provide the patient no benefit. Correcting cell physiology is not itself a benefit to the patient. Incompetent dying patients do not become agitated or tense with malnutrition or dehydration, nor does their affect improve when artificial nutrition or hydration corrects the cellular abnormalities. Artificial feeding would be warranted by even quite uncertain benefits if there were no countervailing harms. However, for some patients, substantial harms are likely.<sup>30</sup> For a few patients, the interventions are predictably going to lead to much distress and be fairly ineffectual because of the patient's concomitant illness. For a few others, the harms entailed, such as infections, limitation of the freedom to move around, and pain, are predictably substantial. For yet a few more, the correction of fluid balance and nutrition to the usual physiological normal range is itself likely to cause harm, as it would for the patient who would thereby be made more lucid and able to experience the anguish of a particularly distressing mode of dying or the patient for whom the "normal" amount of fluids leads to pulmonary edema

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(1987).

<sup>30</sup> See, e.g., Paris and Fletcher, Infant Doe Regulations and the Absolute Requirement to Use Nourishment and Fluids for the Dying Infant, 11 Law, Medicine & Health Care 210 (1983); Lynn and Childress, Must Patients Always be Given Food and Water? in By No Extraordinary Means, Lynn, ed. 1986. (1986); Zerwekh, The Dehydration Question, 13 Nursing, 47 (Jan.1983).

and the dreadful feeling of suffocation as death draws near. Perhaps the most common harm of insisting upon sustaining life by using artificial means to provide nutrition and hydration is that doing so often entails moving the patient into (or keeping the patient within) a hospital. For many patients, being at home or in a long-term care facility is more comforting and comfortable, while the hospital environment may be alien, frightening, limiting to freedom, and possibly even hazardous due to iatrogenic **complications.**<sup>31</sup> If the society were to insist upon providing life-sustaining fluids and food to incompetent persons irrespective of harms such as these, then a needless barrier will have been erected against the peaceful dying at home that many people would prefer.

The primary reason given in support of a categorical requirement to provide hydration and nutrition is that it is somehow different from other kinds of treatment. It is basic care that cannot be foregone. It is true that the provision of food and fluids is one of the fundamental ways of caring for people, yet as described above, the provision of medical nutrition and hydration may not always provide benefits to patients. Medical procedures to provide nutrition and hydration are more similar to other medical procedures than

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<sup>31</sup> See, e.g., Jahnigen, Hannon, Laxson, and LaForce, Iatrogenic Disease in Hospitalized Elderly Veterans, 30 *J. Am Geriatrics Soc* 387 (1982); Steel, Gertmen, Crescenzi, and Panderson, Iatrogenic Illness in a General Medical Service at a University Hospital, 304 *N Engl J Med* 638 (1981).

to typical human ways of sharing meals. Their benefits and burdens ought to be evaluated in the same manner as any other medical procedure. Whenever possible, normal spoon feeding can be continued even though it is expected to be nutritionally inadequate. This avoids the burdens of artificial feeding while still keeping the patient visible part of the human community of sharing food and keeping open the possibility that the prognosis is in error and the patient might have prolonged survival.

In an effort to simplify decision-making, some would also argue that certain patients by virtue of their prognoses must be excluded from decisions to forgo life-sustaining therapy. For example, some would argue that only patients who have a terminal condition or are imminently dying can be allowed to forgo life-sustaining treatment. Yet such a rule would require either the state acknowledge that some patients are required to be treated suboptimally in order to serve state interests or that it be true that all life-sustaining treatments prior to some arbitrary time before death are in fact beneficial (and, incidentally, that this time period can be discerned). Some life-sustaining treatments for those who are not close to dying are clearly not beneficial to some patients, so a reason for suboptimal treatment must be in the state's other interests. Decisions which accept a substantial reduction in likely survival (following Conroy, for example, more than about a year) might well be obliged to

have additional review for the state can define some group at high risk of error and need of protection. However, the standards by which decisions are to be made should remain the same: what course serves the patient best, as the patient would define his or her interest. No state interest seems adequate to overcome the patients interest in having the best possible future that medical care can provide.

Not only is a categorical prohibition contrary to a patient-centered ethic, but it makes very little sense in the context of actual medical decisions. The goal of any medical decision is to promote the well-being of the patient. It is always necessary to weigh the relevant benefits and harms, not only when the patient approaches death. When, in fact, in the continuum from birth through sickness and death does a patient warrant being labeled "terminal"? When does death become "imminent"? As a Virginia court noted, a narrow understanding of imminence may undermine the very intent of laws which allow people to forgo the artificial prolongation of life. The court wrote, "It is precisely people like... this patient who lie between life and death, enjoying nothing of the sweetness of life, while her body slowly gives up its remaining functioning to the advance of a brain tumor, whom the legislature seeks to protect from the indignity of the artificial prolongation of life."<sup>32</sup>

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<sup>32</sup> Hazelton v. Powhatan Nursing Home, Inc., No. CH 98287 (VA. Cir. Ct. Fairfax County, August 29, 1986), order signed (Sept. 2, 1986), (Fortkort, J.), appeal denied, Record

Some also seek to limit the range of choices to forego life-sustaining treatment according to some calculation of the precise cause of death. Such precision is usually impossible in medicine. There are usually long causal links to death which include multiple factors. In a complex case of multiple co-morbidities, as is common in these patients, no single cause of death is descriptively adequate. Pointing to the deliberate foregoing of intervention as the cause of death, rather than to the underlying lethal condition that gave rise to the opportunity to intervene, would be but another example of the normative aspect of the judicial inquiry into causation. The society must first decide that foregoing a life-sustaining medical intervention is to be characterized as blameworthy and therefore of interest to those who enforce the criminal laws. Unless society dictates that specific patients shall be kept alive by unwanted and harmful life-sustaining intervention, then the relevant cause of death when life-sustaining treatment is foregone is best given as the underlying lethal process, not the foregoing of treatment. In Mrs. Browning's case, the stroke that rendered her too unresponsive to swallow and which would have killed her promptly in any previous era should be named as the cause

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No. 860814 (Va. Sept. 2, 1986), 6 Va. Cir. Ct. Op. 414 (Aspen 1987).

of death even if the time of death was delayed for two years or more by a treatment that created an artificial plateau in the course of her dying.

IV. PROCEDURES PUT IN PLACE TO MAKE DECISIONS SHOULD BE SENSITIVE, PRACTICAL, AND RESPONSIVE TO THE VALUES AND PREFERENCES OF INDIVIDUAL PATIENTS.

Even when a court adopts a reasonable, thoughtful view on the substantive standards described above, good decision-making can be rendered nearly impossible if the required procedures are too complex, time consuming, and otherwise burdensome. Indeed, this scenario has recently unfolded in New Jersey<sup>33</sup> and New York,<sup>34</sup> where certain procedures to follow foregoing life-sustaining treatment have become so onerous that they cannot routinely be implemented.

One of the most important features of procedures for making decisions on behalf of incompetent patients is that they are made using the best possible information about prognoses and patient preferences. Adequate information about the patient's medical condition, range of choices, and personal values and preferences, must be incorporated. Those significant issues that allow factual resolution should be

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<sup>33</sup> Letter of Hector M. Rodriguez, Acting Ombudsman, State of New Jersey, (August 30, 1988), ("Decisions to Withdraw or Withhold Life-Sustaining Medical Diagnoses or Treatment from Patients Age 60 and over)," and Commission on Legal and Ethical Problems in the Delivery of Health Care, "Office of the Ombudsman: Policy Statement for Triennial Report," December 29, 1988.

<sup>34</sup> In re Westchester County Medical Center 72 N.Y.2d 517, 631 N.E. 2d 607 (1988).

resolved at each level. The court as well as the physician must know whether Mrs. Browning communicates and evidences pain or pleasure. These are factual questions that should not remain ambiguous.

Additionally, decisions should involve those closest to the patient such as family, friends, and care-providers. They are generally loyal to and concerned about the patient in ways that strangers can never be and they also know the patient's values and preferences better than anyone else. Efforts to make decisions for incompetent patients should be as respectful as possible of the integrity of the family relationships. In addition, decision-making must respect the moral integrity of caregivers and the societal need for caregiving agencies to continue to function. Courts should be utilized only in the unusual cases, with little if any judicial involvement in routine cases. As the AGS Policy states,

We encourage legislation at the state level to insure the availability of a range of options for patients, including statutes defining durable powers of attorney for health and carefully structured living wills. Such legislation would provide authority, in most cases, for decision-making by appropriate surrogates and physicians without needing formal guardianship proceedings.<sup>35</sup>

When cases are brought to court for decision-making, inquiry must extend to ascertaining the course that best

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<sup>35</sup> The American Geriatrics Society, Position Statement: Medical Treatment Decisions Concerns Elderly Persons (1987).

serves the patient's overall well-being, with due consideration to the likely length of life and the circumstances of that life, for each of the available treatment alternatives. Evidence that the responsible health care professionals and the patient's family and friends have strived to achieve this careful balancing of considerations in order to further the patient's best interests should occasion substantial deference by courts. Furthermore, cases where the chosen course of action (whether or not life-prolonging) is uncontroversially in the interests of an incompetent patient should not routinely be brought to court. By indicating respect for procedures developed by practitioners and health care institutions, courts could encourage a high standard of careful decision-making. Indeed, courts confronted with an incompetent patient with a surrogate and with multiple alternative plans of care should ordinarily limit themselves to four issues: 1) Are the patient's likely futures understood as well as reasonably possible; 2) Is a choice among potential plans of care dictated by the patient's known preferences or evident best interests?; 3) If not, is the surrogate appropriately granted discretion among alternatives?; and 4) Is there any interest of others (dependents, caregivers, or the state) that bars effectuation of the choice that best serves the patient?

Procedures mandated by courts, legislatures, or regulators must be responsive to the extraordinary frequency



with which they must be implemented. Probably most people will have a substantial period of incompetency during their adulthood, whether precipitated by acute or chronic illness and whether associated with a fatal illness or not. During that period of incompetence, decisions that might affect the length of life will arise, often more than once. Most such decisions are made and made well among those who love the patient and those who provide health care for the patient. In Washington, D.C., for example, less than two percent of such cases are brought to court even for determination of incapacity or for management of assets.<sup>36</sup>

There is no evidence that a pattern of error exists at present which allows patients to die too readily. Indeed, all societal incentives pull toward extending life, which pays the providers, avoids most feelings of guilt among family and caregivers over not having tried hard enough, and avoids most causes of review. The fear of providers, especially, of the penalties that can arise from a retrospective review which might interpret a particular choice as being in error is substantial and pervasive. Health care providers are very risk-averse, both by nature of character (being cautious and precise) and of prudence (economic penalties are severe merely for allegations of serious error). Legal requirements for reporting abuse,

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<sup>36</sup> Hearings on the Health Care Decisions Act Before the Committee on the Judiciary, City Council of the District of Columbia (Sept. 16, 1987) (testimony of Joanne Lynn).

investigating deaths, and reviewing quality of care in organized health care do make it reasonably likely that cases of serious error would be discovered and penalized.

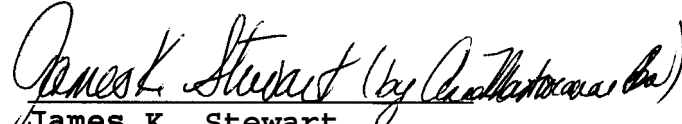
Awareness of the potential penalties acts to ensure careful decision-making. In fact, it is much more common for patients and families to complain of being overtreated than undertreated, especially when overtreatment extends life.

While errors still may occur, as they may in any human endeavor, prudent policy requires that the risks of error be balanced against the burdens, including newly induced errors, that are imposed by any new procedure. Clearly, formal and public review of all cases would be so burdensome and costly that decisions would effectively be deferred beyond the end of life. There may be cases where the risks of error are so substantial that they merit routine review by additional consultants, ethics committees, or courts. But such categories would rely upon data as to the frequency of cases and errors and the costs and benefits of various strategies for review. These data are never before a court in a particular case; instead, they are properly part of a legislative process. This deficiency in the record presented in any court case should give courts pause in establishing procedures that seem merited by the case which is before the court but which has unknown merit as a matter of policy.

CONCLUSION

For the foregoing reasons, the amicus respectfully requests that the court answer the certified question in the affirmative.

Respectfully submitted,

  
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July 14, 1989

CERTIFICATE OF SERVICE

I hereby certify that a true and accurate copy of the foregoing has been furnished to Larry J. Gonzales, Esq., attorney for Sunset Point Nursing Center, 911 Chestnut Street, Clearwater, Florida 34617-1368; to George J. Felos, Esq., Attorney for Doris F. Herbert, 380 Main Street, Suite 200, Dunedin, Florida 34698; and to James T. Russel, State Attorney, P.O. Box 5028, Clearwater, Florida 34618, by certified mail, postage prepaid, this 14th day of July, 1989.

  
ANNA MASTROIANNI BOE