

Presentation to Senate Committee on Aging

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I. Amending Connecticut Legislation (PA 91-283, Amended 10/1/06) To Address Injustices for the Dying and the Living and Preserve the ‘Right of Self-Determination’

II. Proposed Amendments to the Connecticut Public Acts Chapter 368, entitled, “Removal of Life Support Systems”

Prefatory statements and Reference to Authorities

Issues to Consider and Address:

(1) Living wills must be more explicit about a patient’s demands to withdraw life support, consistent with statutory intent.

Existing Connecticut (CT) law is confusing and self-contradictory in many ways (is it the patient’s “instruction” or “direction” or is it the “physician’s views” of what must be done? Is a living will intended to be followed or just discardable guidance? Presently-approved forms of living wills are contradicted by the discretion and powers given to physicians.

(2) Confine the physician’s role to what truly requires medical expertise: determining the condition of the patient and assistance with end-of-life (EOL) decisions. The patient by living will or a health care surrogate should decide on withdrawal of life support systems.

(3) There are no sanctions or pressure on physicians to comply with living wills; that should be rectified.

(4) “Connecticut’s existing statutes require only minor modifications to be more consistent with those in other jurisdictions and with established national standards-of-care. ...A more useful statute might change 52965 of the Connecticut code to “A surrogate may consent to an order not to resuscitate or to withdraw life-sustaining therapies if the patient is, in the opinion of caregivers, unlikely to recover, and the order is consistent with the patient’s wishes (as specified in advance directives and/or as shared with the surrogate).” . . .Also, ...physicians would be better served if the clause in S19a-571 “the attending physician deems the patient to be in terminal condition or, in consultation with a physician qualified to make a neurological diagnosis who has examined the patient, deems the patient to be permanently unconscious” is simply omitted. By eliminating the use of the arbitrary term “terminal” as the litmus test for withholding or withdrawing care, we will have taken an important step to realizing greater patient self-determination while protecting our physicians who seek to serve the best interests of each patient.”¹

1. “Critical Care Physicians’ Practices and Attitudes and Applicable Statutes regarding Withdrawal of Life-Sustaining Therapies” Constantine A. Manthous MD Conn Med 69: Aug. 2005.

(5) Address Alzheimer's and other Senile Dementia conditions.

This is important, pioneering work. No state has yet touched Alzheimer's, nor has any court. Timidity has triumphed. But the impetus to deal with this terrible disease and its consequences is gathering steam in other jurisdictions. CT would be courageous in leading the way.

Alzheimer's should be recognized for what it is: a fearsome disease because of its length and what it does to one's dignity and assets and how it distorts the memories that family and friends have of you.. It kills you cognitively before it kills you physically, effectively causing two deaths: socially and physically.

Is it legal to proceed with this aspect? Yes. The U. S. Supreme Court has encouraged states to "innovate", to experiment with EOL issues. The only possible impediment against addressing Alzheimer's in a living will is a law against "assisted suicide". Yet even this is within the power of states to rectify. In 1997 the United States Supreme Court, in the case of *Glucksberg v. Washington*, rejected the application of the concept of assisted suicide to physicians' assistance in the withholding or removal of life support systems at the request of patients (those acts being deemed fundamental rights of patients to "bodily integrity", to refuse to have "useless and futile and degrading things done to them") And just last year, when it had the chance to strike down Oregon's physician-assisted suicide law (which permits lethal injections for terminally ill patients who request it), the Supreme Court upheld it in a challenge by the U.S. Attorney General.

This seems to be clear confirmation that the Supreme Court is leaving EOL issues to the states --- like other "cultural" issues.

Another issue (and unexplored territory): can state statutes include withdrawal of "normal nutrition and hydration" as distinguished from withdrawal of "artificial feeding" by a G-tube? The distinction between "normal" and "artificial" in trying to determine whether withdrawal of one is palliative and the other is criminally punishable ("assisted suicide") seems artificial. None of the courts that have dealt with that issue (including Connecticut's) had before it either a living will requesting withdrawal of food and water, nor an explicit state statute approving withdrawal of food and water (coupled with palliative care, under the dire circumstances of a progressive cognitive deterioration), nor even a case involving Alzheimer's Disease or other senile dementia.

While there is no unequivocal confirming case, there is enough judicial encouragement and sympathetic language in multiple cases dealing with EOL issues to warrant confidence that a state that has the courage to deal with Alzheimer's in a forthright, comprehensive and sensitive manner, emphasizing the rights and wishes of the individual, will be applauded --- and upheld.

I. Amending Connecticut Legislation (PA 91-283, Amended 10/1/06) To Address Injustices for the Dying and the Living and Preserve the ‘Right of Self-Determination’

We Are Growing Older - Why we need Effective Living Wills.

As we octogenarians approach death, End of Life (EOL) issues have assumed increasingly serious proportions because of frailty, illness, injury, cost, and life withdrawal.

The development of Living Wills (Advance Directives) in the last few decades has been an attempt to prevent the painful toll of being kept alive against one’s will. Connecticut’s “Living Will Law” (Public Act 91-283, Amended October 1, 2006) is such an effort, but woefully unreliable. Although the law is of enormous importance for both the dying and the living, it fails to deliver the control needed by the individual to avoid the Scylla of long insufferable life and the Charybdis of financial ruin. As a result, EOL is fraught for each of us, vulnerable and frail, with the loss of personal identity, family relationships, and insufferable emotional or physical pain. And as a coup-de-grace, all of us, dying and living, are inflicted with degrading, financial devastation.

Another major issue is cognitive death. A person who survives illness or injury, but has ceased to exist socially, is isolated, without personal identity, or capacity to relate to family or friend. The consequences of the disintegration of such a lost individual are costly and should be able to be avoided by an enforceable Living Will.

The law must change to make effective a person’s demands to die in comfort, with dignity and without interference. “Living Wills” legislation must be redefined to protect the wishes of the dying and their families against societal interferences that result in the costly, inhumane prolongation of life instead of supportive palliative care.

We wish to amend (Public Act 91-283):

(1) To improve the efficacy and certainty of the exercise by incapacitated patients in Connecticut of the right of self-determination concerning the refusal or withdrawal of life support systems and

(2) Extend the same right of self-determination to those patients afflicted with Alzheimer’s Disease or other forms of incurable or progressive senile dementia.

Is it necessary to tell anyone over age 55 about the disasters of Aging and Alzheimer’s?

“What Are We Going To Do With Dad?”²

“In the United States today there are 35 million geriatric patients -- defined as over the age of 65. Of these, 4.5 million are older than 85, now characterized as the “old old” [of which, in Connecticut, we estimate there may be some 45-50,000 Alzheimer patients]. As we baby boomers go about our lives, frozen into our routines of work and family responsibilities, a vast inland sea of elders is building. By 2020 there will be an estimated 53 million Americans older

2. “What Are We Going To Do With Dad?” by Jerald Winakur MD, Center Humanities and Ethics at the University. of Texas

than 65, 6.5 million of whom will be “old old.” Many of you will be among them.

America will be inundated with old folks, each with a unique set of circumstances, medical and financial...there is one inescapable truth: Our parents will become our children if they live long enough.

One day I will get a frantic call from my mother that my father is on the floor and crying out in pain. I will race over there. I will find that one of his legs is shortened and externally rotated. His hip is broken. I will call my brother and tell him all the reasons why we should not send him to the hospital: He might not recover from the surgery -- indeed, he might die on the table, given his bad heart. If he does survive, he will spend days in the ICU, probably on a respirator. At best he will end up in a nursing home, bedridden, at the mercy of overworked, underpaid aides. He will descend deeper into disorientation, require medications to keep him from harming himself, and die anyway in a few months -- or perhaps a year or two if he is unfortunate and the care is better than average.

Compounding all of this is the sad and frustrating fact that our government appears to have no policy vision for long-term elder care. It's as if our leaders wish -- perhaps reflecting our collective yearnings as vain, youth-worshiping society -- that when the time comes, the elderly will take their shuffling tired selves, their drooling and incontinence, their demented ravings, their drain on family and national resources, and sprawl out on an ice floe to be carried off to a white, comforting place, never to be heard from again.”

“More Americans Discussing, and Planning, End-of-Life Treatment”³

“An overwhelming majority of the public supports laws that give patients the right to decide whether they want to be kept alive through medical treatment. And fully 70% say there are circumstances when patients should be allowed to die, while just 22% believe that doctors and nurses should always do everything possible to save a patient. Most Americans believe it should be up to individuals – not the government or medical professionals – to ultimately determine their end-of-life medical decisions. People are increasingly thinking about –and planning for – their own medical treatment in the event of a terminal illness or incapacitating medical condition. Public awareness of living wills, already widespread in 1990, is now virtually universal, and the number saying they have a living will has more than doubled – from just 12% in 1990 to 29% today. People also are much more willing to discuss sensitive end-of-life issues with their loved ones than they were a generation ago. Nearly seven-in-ten (69%) of those who are married say they have had a conversation with their husband or wife about their spouse’s wishes for end-of-life medical care.”

“Care in Old Age: Confronting the Inevitable”⁴

Even among severely or terminally ill patients, the federal Agency for Healthcare Research and Quality has found, fewer than half have advance directives in their medical records. It's not hard to see why. Frailty, disease, ultimately death - what older person wants to contemplate those? Delay and denial seem preferable But consider the consequences of that distaste. I know a Baltimore woman whose mother blithely rejected all such discussion.

3. “More Americans Discussing, and Planning, End-of-Life Treatment” PEW Research Center, 1/5/06.

4. “Care in Old Age: Confronting the Inevitable” Paula Span NYTimes - 1/21/0

5. “Cardinal Says Patients Should Have Right To Die” NY Times - (Agence France-press) 1/22/07

“A will is just something for children to fight over,” she insisted, right through her sons. Now, Alzheimer’s disease makes her no longer competent to sign any legal document, even if she could be persuaded to.”

“Cardinal Says Patients Should Have Right To Die”⁵

“In a letter in an Italian newspaper on Sunday, Cardinal Carlo Maria Martini, the influential former archbishop of Milan, urged the Vatican to allow terminally ill patients who ask “in all lucidity” the right to withdraw life-sustaining medical treatment. Cases like that of Piergiorgio Welby, a muscular dystrophy patient who sought to have himself removed from the respirator that had kept him alive for years, “will be more frequent,” said the 79-year-old cardinal, who suffers from Parkinson’s disease, and the church should be more attentive to them, notably at the pastoral level.” He said that while the distinction between euthanasia, which the Vatican rigidly opposes, and the refusal of excessive care is sometimes unclear, “the wishes of the patient cannot be ignored.” Mr. Welby died last month when a doctor in Rome unplugged his respirator. He had been unable to end his life legally because there was no law permitting it. The Diocese of Rome then denied permission for a church funeral.

“Variability of Statutes Regarding Withdrawal of Life- Sustaining Therapies” (excerpts)⁶

“Sixty-six critical care physicians from six states responded to a questionnaire about their practices regarding withdrawal of life sustaining therapies.

In summary:

Of patients in whom they had withdrawn life-sustaining therapies, 55% were terminal, 20.5% weren’t necessarily terminal but advance directives were used to withdraw care and 22% weren’t necessarily terminal but families requested that life support be withdrawn.

Respondents were unanimous that statutes should provide for binding advance directives for non-terminal illnesses when either the likelihood of survival was low (threshold specified by patient) or the quality of life following critical illness was unacceptable to the patient.

More than 70% of respondents agreed that advance directives regarding terminal illness should apply to patients with advanced Alzheimer’s Disease that has progressed to incompetence.

... Because clinicians themselves cannot agree conclusively on what constitutes a terminal condition, laws predicated on this designation may be arbitrary. Even if the “terminal” designation is a valid construct (and it would need to be clearly defined), some critically ill patients in whom withdrawal of care is considered are unlikely to satisfy tightly defined criteria.

(Regarding Connecticut law):

...Connecticut’s statute is inconsistent with the common medical practice of all states sampled of withdrawing life-sustaining therapies when the chance of meaningful recovery is very low and such therapy is inconsistent with the patient’s previously stated wishes as voiced by patients’ loved ones. Accordingly, the Connecticut statute may at times be at odds with the ethical and legal obligations of physicians to their patients. ...To continue invasive life-sustaining therapies of an incapacitated patient whose surrogates are acting in good faith and wish to withdraw might constitute legal grounds for battery of the patient. Additionally, the Connecti-

6. “Critical Care Physicians’ Practices and Attitudes and Applicable Statutes regarding Withdrawal of Life-Sustaining Therapies” Constantine A. Manthous MD Conn Med 69: Aug. 2005.

cut law does not state that physicians will be punished if they fail to meet the criteria (including deeming the patient terminal), but rather that they will be protected if they meet all criteria.

...In the coming years...the number of cases of dementia is likely to increase. Most busy intensive care units admit several patients with advanced Alzheimer's each month, initiating a trial of invasive life-sustaining therapies. Often critical care therapies are begun with little information as to whether the patient would have wanted such treatment because patients had not clarified their wishes before they lost capacity. ...However, since advanced dementia will most likely increase in prevalence, our state's caregivers might benefit from greater clarity in statutes regarding end-of-life issues in such patients"

Conclusions:

Powerful, intrusive forces (legal, professional, ethical, religious, familial, and financial) often make dying the painful process it should not be:

(1) Physicians are dedicated, by tradition, to the saving and preservation of lives, 'doing no harm', but there is little recognition of the harm caused to patients and their families by unnecessarily prolonging life.

(2) Many religions argue that life is 'God-given', should not be taken, but should be preserved until the last spark of life is extinguished.

(3) Loving family members may misguidedly insist on preserving life, despite the expressed wishes of the dying, forcing them to live, afflicted for prolonged periods of time, with the awful consequences of a disfiguring or incapacitating illness.

(4) Personal and Professional Care-givers and Institutions, rightly or wrongly, often profess reluctance to carry out the demands of a Living Will, under perceived threat of legal retaliation and despite the fact that "the Constitution encompasses a due process liberty interest in controlling the time and manner of one's death---that there is, in short, a constitutionally recognized `right to die.'" Glucksberg et al - Supreme Court (1997) As insulation, reacting to these threats, real or imagined, some Hospital Ethics Committees (Texas Legislation 1999), not the patient (or legally designated surrogate), are given the right to decide whether to allow death (DeBakey case, December, 2006).

(5) Agencies, protective of the disabled, may intervene to protect life.

(6) Political Movements, such as the Religious Right, demand that everyone hue to their basic tenet to preserve life, regardless of others' beliefs and irrespective of patient desires (as witness the extraordinary Congressional attempt to intervene in the Schiavo case, 2005).

(7) Except for Oregon's limited physician-assisted suicide law, state laws view the efforts of loved ones....as murder or manslaughter to assist in the patient-desired death of the hopelessly deteriorated or dying person with no hope of recovery.

(8) Advances in medical knowledge make it possible to extend life almost indefinitely, to deteriorated, helpless and hopeless individuals---destroying the quality of their lives, effectively warehousing them.

(9) The seemingly endless increase in medical care costs that threatens to inflict financial ruin on the patient who lives long enough, and on their families and charitable beneficiaries, if any, creating financial and emotional turmoil for all involved.

(10) Social (cognitive) death, the result of progressive mental deterioration of a living

person who has lost his/her personal identity and ability to relate to others, should be recognized as a “terminal” condition legally entitled to end.

Proposals

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We propose:

(1) To eliminate the widespread confusion which currently exists among physicians, bioethicists, patients and their advocates concerning the scope and application of Connecticut’s living will law (“CT Law”).

(2) To remove existing impediments imposed by CT Law on, and the grant of full respect to, the rights of patients, as declared by the United States Supreme Court, to “bodily integrity”, to be free of “unwanted touching”, and to have their wishes not to have “useless and futile or degrading things” done to them.

(3) To balance the release from civil and criminal liability granted by CT Law to those licensed physicians and medical facilities who respect the wishes of patients who have expressed preferences concerning the withholding or withdrawal of life support systems by adopting a correlative imposition of liability upon those licensed physicians and medical facilities who do not respect the wishes of such patients.

(4) To reduce the cost to public authorities, medical facilities, the public, and patients and their families by encouraging a speedier response to clearly expressed patient’s requests.

(5) To provide palliative relief and end-of-life care, comparable to that extended to incapacitated patients suffering from physical terminal conditions to those afflicted with Alzheimer’s, who are suffering from cognitive terminal conditions (“social death”), and to protect such victims and their families from the extraordinarily devastating financial and psychological consequences suffered by them over long periods of time.

(6) To promote vigorously the importance of Living Wills and authorize Connecticut residents to execute them through audio-visual means, so long as they can be authenticated and witnesses appear therein.

II. Proposed Amendments to Chapter 368w of the Connecticut Public Acts, entitled, “Removal of Life Support Systems”

(1) Section 19a-570. Definitions is hereby amended as follows:

(1) Subsection (1) is hereby deleted and the following is substituted therefor:

(1) “Life support system” means any medical or other procedure or intervention which does not contribute toward successful treatment of an individual’s illness, but only serves to postpone the moment of death or maintain the individual in a state of permanent unconsciousness or, in the case of an individual afflicted with Alzheimer’s Disease, maintain the individual in a state of progressive deterioration of cognitive capacity. Such procedures shall include, but are not limited to, mechanical or electronic devices, including artificial means of providing nutrition or hydration and, in the case of an individual afflicted with Alzheimer’s Disease, shall also include non-artificial (normal) means of providing nutrition or hydration.

(2) Subsection (3) is hereby amended by adding after the words “attending physician;” the following: in the case of an individual afflicted with Alzheimer’s Disease who has signed and delivered a living will, “terminal condition” shall mean the point in the progressive deterioration of that individual’s cognitive capacity beyond which the individual has declared in such living will that he or she does not want to live.

(3) A new subsection (10) shall be added, reading as follows:

All references to “Alzheimer’s Disease” shall include other irreversible senile dementia illnesses with loss of cognitive capacity.

(4) Section 19a-571 is hereby deleted and the following is substituted therefor: Sec. 19a-571. Liability re removal of life support system of incapacitated patient. Compliance with instructions or wishes of patient. (a) Subject to the provisions of subsection (c) of this section, any physician licensed under chapter 370 or of any licensed medical facility who or which removes or causes the removal of a life support system of an incapacitated patient shall not be liable for damages in any civil action or subject to prosecution in any criminal proceeding for such withholding or removal, provided (1) that the decision to withhold or remove has been made in compliance with instructions given by the patient or by the patient’s health care agent or by the patient’s attorney in-fact for health care decisions or by a court of competent jurisdiction called upon to resolve disputes over the meaning of the patient’s instructions, as the case may be, and that the actual withholding or removal is timely done in accordance with the best standards of medical practice, including the provision of adequate palliative care; (2) that, in cases of other than Alzheimer’s patients, the attending physician deems the patient to be in a terminal condition or, in consultation with a physician qualified to make a neurological diagnosis who has examined the patient, deems the patient to be permanently unconscious. The attending physician shall allow a patient’s instructions expressed in any document executed in accordance with sections 19a-575, 19a-575a and 19a-575b, if any such document is presented to, or in the possession of, the attending physician at the time the decision is made to withhold or remove a life support system. If the patient’s instructions have not been expressed in a living will, the attending physician shall determine the wishes of the patient by consulting any statement made by the patient directly to the attending physician and, if available, the patient’s health care agent, the patient’s next of kin, the patient’s legal guardian or conservator, if any, person designated by the patient in accordance with section 1-56r and any other person to whom the patient has communicated his wishes, if the attending physician has knowledge of such person. All persons acting on behalf of the patient, including the attend-

ing physician, shall act in good faith. Except for any patient, including a patient suffering from Alzheimer's Disease who has executed a living will containing contrary instructions, and, with respect to other patients, until the attending physician discovers that the patient's wishes were to the contrary, if the attending physician does not deem an incapacitated patient to be in a terminal condition or permanently unconscious, beneficial medical treatment, including nutrition and hydration, must be provided.

(b) A physician qualified to make a neurological diagnosis who is consulted by the attending physician pursuant to subdivision (2) of subsection (a) of this section shall not be liable for damages or subject to criminal prosecution for any determination made in good faith and in accordance with the usual and customary standards of medical practice.

(c) The exculpation from civil and criminal liability accorded to any licensed physician and licensed medical facility in subsection (a) of this section shall be unavailable to any licensed physician or licensed medical facility who or which does not in good faith comply, to the best of such physician's or medical facility's ability, with the patient's instructions or wishes, as the case may be; provided, however, that it shall be a defense that a bona fide physical or mental or emotional condition substantially interfered with or prevented compliance with the patient's instructions.

(d) in the case of an infant, as defined in 45 CFR 1340.15(b) the physician or licensed medical facility shall comply with the provisions of 45 CFR1340.15(b)(2) in addition to the provisions of subsection (a) of this section.

(5) Section 19a-575. Form of Document is hereby amended as follows:

(a) In the first paragraph of the Document the last word "wishes" shall be replaced by the word "instructions";

(b) In the following paragraph, following the "(Name)", the word "request" shall be replaced by the word "direct".

(c) In the sentence, "This request is made, after careful reflection, while I am of sound mind", the word "request" shall be replaced by the word "direction."

(6) Section: Connecticut residents are authorized to create Living Wills by audio-visual means, so long as they can be authenticated and witnesses appear therein.

(7) A new section 19a-575b shall be added, reading as follows:

Sec. 19a-575b. Form of document re health care instructions dealing with both physical and cognitive incapacity, appointment of health care agent, attorney-in-fact for health care decisions, designation of conservator of the person for future incapacity and anatomical gift. Any person eighteen years of age or older may execute a document which contains health care instructions, the appointment of a health care agent, the appointment of an attorney-in-fact for health care decisions, the designation of a conservator of the person for future incapacity and a document of anatomical gift. Any such document shall be signed and dated by the maker with at least two witnesses and may be in the substantially following form:

THESE ARE MY HEALTH CARE INSTRUCTIONS.
MY APPOINTMENT OF A HEALTH CARE AGENT,

MY APPOINTMENT OF AN ATTORNEY-IN-FACT
FOR HEALTH CARE DECISIONS,
THE DESIGNATION OF MY CONSERVATOR OF THE PERSON
FOR MY FUTURE INCAPACITY AND MY DOCUMENT OF ANATOMICAL GIFT

To all persons:

These are my health care instructions, including those concerning the withholding or withdrawal of life support systems, together with the appointment of my health care agent and my attorney-in-fact for health care decisions, the designation of my conservator of the person for future incapacity and my document of anatomical gift. All persons, including my attending physician, shall comply with any decision made by my health care agent, attorney-in-fact for health care decisions or conservator of my person, if I am unable to make a decision for myself.

I,, write this document with an awareness that the United States Supreme Court, in the 1997 case of *Glucksberg v. Washington*, has approved a physician's honoring a patient's refusal to begin or a patient's wish to withdraw "life-sustaining medical treatment" and a patient's desire to have the physician "cease doing useless and futile or degrading things to the patient when [the patient] no longer stands to benefit from them." I am informed that the Court grounded its decision on "well-established, traditional rights to bodily integrity and freedom from unwanted touching." Beyond that, I know that the Court has approved the provision of "aggressive palliative care" to alleviate a patient's [physical] pain. I understand that in all those approved instances the result of the physician's act, whether desired or not, would be the death of the patient. I know, too, that some justices of the Court in that case viewed kindly the notion that the freedom to refuse "a particular kind of unwanted treatment" embraces an individual's "interest in dignity, and in determining the character of the memories that will survive long after her [his] death."

I am further aware that the Supreme Court of Connecticut, in the 1989 case of *McConnell v Beverly Enterprises*, expressed similar views, declaring that the "right to refuse medical treatment is a right rooted in this nation's fundamental legal tradition of self-determination, and "no right is more sacred . . . than the right of every individual to the possession and control of his own person, free from all restraint or interference of others, unless by clear and unquestionable authority of law." The Court further noted that "Many of the cases . . . have urged legislatures to enact guidelines for appropriate private decision-making in these heart-rending dilemmas."

It is with the above judicial declarations in mind and because I do not want to be the subject of one of those "heartrending decisions" that I express the following directive:

If my condition is deemed terminal or if I am determined to be permanently unconscious, I be allowed to die and not be kept alive through life support systems. By terminal condition, I mean that I have an incurable or irreversible medical condition which, without the administration of life support systems, will, in the opinion of my attending physician, result in death within a relatively short time. By permanently unconscious I mean that I am in a permanent coma or persistent vegetative state which is an irreversible condition in which I am at no time aware of myself or the environment and show no behavioral response to the environment. The life support systems which I do not want include, but are not limited to: artificial respiration, cardiopulmonary resuscitation and artificial means of providing nutrition and hydration and, in the case of Alzheimer's Disease or other senile dementia, as hereinafter more fully explained, ordinary means of nutrition and hydration. I do want sufficient pain medication

to maintain my physical comfort. I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged.

In the succeeding paragraphs the use of the phrase “my cognitive capacity” shall mean my ability to think, to understand, to remember, and to experience joy, together with my ability to convey to others thoughts, understanding, memories and joy.

If I should be afflicted with any disease or injury which substantially destroys my cognitive ability, and competent medical opinion concludes (a) that the destruction of my cognitive ability is neither reversible nor curable at that time and (b) that reversibility or cure is not confidently predictable within the immediate future (meaning months, not years), then I do not wish any life support, systems, “life-saving” or “life-prolonging” techniques or devices of any sort connected or applied to me and, if any such systems, techniques or devices have been connected or applied to me, I wish them promptly removed. The life support systems which I do not want include, but are not limited to: artificial respiration, cardiopulmonary resuscitation and artificial and ordinary means of providing nutrition and hydration; with respect to the withdrawal of ordinary means of nutrition and hydration, it may be gradual -- such as, over a period of weeks. I do want sufficient pain medication to maintain my physical comfort. I do not intend any direct taking of my life, but only that my dying and the continued deterioration of my cognitive capacity not be unreasonably prolonged.. .

Further, if I should be afflicted with any disease or injury (including, without limitation, Alzheimer’s disease and other forms of senile dementia) which will, according to competent medical opinion, over a course of time gradually and increasingly erode my cognitive capacity, and competent medical opinion concludes that (a) the destruction of my cognitive capacity is neither reversible nor curable at that time and (b) reversibility or cure is not confidently predictable within the immediate future (meaning months, not years), then I want this miserable condition interrupted and brought to a conclusion as rapidly as possible, even though the consequence of the actions taken will result in my death. It is not that I have or will then have a specific desire to die, but, in a distinction the Supreme Court has forcefully recognized, I do not wish to continue to live encumbered with unwanted consequences.

More specifically, I do not want the deterioration or erosion of my cognitive capacity to progress to the point when, as examples, I cannot recognize my loved ones, nor articulate coherent thoughts and sentences, nor remember the names of my children, nor read books, nor watch or listen to television or other media with understanding and enjoyment, nor intelligently discuss an issue with intellectual proportions, nor know when or how to eat and perform personal hygiene on a regular basis without assistance, or remain uncommunicative or babble incoherently or curse erratically or repeatedly or without apparent provocation exhibit anger, antisocial or other bizarre behavior. I want “out” long before any modest combination of these instances or events occurs repeatedly or continuously. As a guide, I suggest that whenever any three of these events have occurred and have been repeated over the course of several weeks the time for the withdrawal of life support has arrived.

In the context and spirit of the Supreme Court’s language, I would consider :(1) my being provided or assisted with nutrition and hydration -- by whatever means -- and (2) personal hygiene by health care personnel on a regular basis (changing diapers, and the like) because I am no longer mentally capable of performing those functions without help; an affront to my personal dignity, “degrading,” and as a breach of my right to “freedom from unwanted touching.” I declare now, while I have the capacity to express these thoughts, that I consider the refusal of any physician, hospital, court, political entity, religious group or doctrine, person or

law to permit me to carry out (or to permit a physician or any other person to assist me in carrying out) my wish to be permanently relieved of the foregoing indignities and degradations a flagrant deprivation of my basic freedom as a human being, and, as surely, a violation of my fundamental rights as an American citizen. The right to determine the memories I leave to my spouse, children, grandchildren and friends as a loving, thinking, caring, vibrant human being – memories unclouded by years of their watching the inexorable deterioration of my cognitive ability -- is singularly and preciously mine.

Further, at the time of this writing, to my knowledge, neither the medical profession nor the courts have recognized nor elevated the mental pain experienced by one's losing his or her cognitive ability to the level of physical pain for which the Supreme Court has authorized "aggressive palliative treatment." I can already feel the beginnings of that psychological or emotional pain as I contemplate my frustration in having difficulty recognizing or speaking to my own children. I want aggressive palliative sedation before that happens.

The critical issue, of course, is when. How does one confidently predict the precise right time? One cannot. The progression and manifestations of dementia, I understand, vary from individual to individual. I can only say that I want relief from the assault on my cognitive capacity long before my persona is suffocated or belittled or humiliated by sustained confusion or frustration or helplessness or by any combination of these elements. Once the disease has been firmly diagnosed as leading to the continuing erosion of my cognitive capacity, I want the decision maker(s) to err on the side of earlier rather than later. It should not be too difficult for my health care agent or for an attending physician or my family or a judge or other appropriate authority, as the case may be, to know that the time has come. Reference should be made to the paragraph above which begins with the words "More specifically", and describes the loss of certain elements of cognitive capacity.

As for method, my preference is to "get it over with" as fast and painlessly as possible. Thus, lethal medication, as is presently approved by the State of Oregon under certain circumstances (and upheld by the Supreme Court), would be optimal. Recognizing my psychological pain (as described above) as equivalent to intense physical pain would suggest aggressive sedation – also acceptable. And the gradual withholding of nutrition and hydration -- and assistance with my own efforts to accomplish the same --, coupled with sedation if necessary to relieve pain or anxiety, would suit me fine. Whatever works best to achieve the result intended, according to the best medical judgment.

Finally, I want to unmistakably counteract what, in my view, is a common, but woefully misguided, notion about the possible "impurity" of the motives of family members who seek to end the life of a parent or other relative, at least in part, for the purpose of inheriting an estate. Because I may be suffering from a disease that progressively diminishes my cognitive capacity, that does not mean that I have made a decision that the prime beneficiaries of my estate shall become hospitals, nursing homes, physicians or lessors of medical devices – as distinguished from members of my family and designated charitable beneficiaries. I do not want my estate to be dissipated in futile efforts to keep me smiling or breathing for the prime benefit of unrelated, unwanted and presently unknown providers, creditors, politicians or the media. My desire and the desires of my intended beneficiaries coincide quite hospitably in this regard: when my active cognitive life is over, they shall inherit without unnecessary waste and as soon as reasonably possible whatever was intended for them, all as expressed in testamentary and other dispositive documents. circum-

stances (and upheld by the Supreme Court), would be optimal.

I fervently hope that by the time these words are read under the solemn conditions to which they are directed, the essential humanity and legality of granting my wishes will be universally recognized.

I appoint to be my health care agent and my attorney-in-fact for health care decisions. If my attending physician determines that I am unable to understand and appreciate the nature and consequences of health care decisions and unable to reach and communicate an informed decision regarding treatment, my health care agent and attorney-in-fact for health care decisions is authorized to:

(1) Convey to my physician my instructions concerning the withholding or removal of life support systems;

(2) Take whatever actions are necessary to ensure that any instructions are given effect;

(3) Consent, refuse or withdraw consent to any medical treatment as long as such action is consistent with my instructions concerning the withholding or removal of life support systems; and

(4) Consent to any medical treatment designed solely for the purpose of maintaining physical comfort.

If is unwilling or unable to serve as my health care agent and my attorney-in-fact for health care decisions, I appoint to be my alternative health care agent and my attorney-in-fact for health care decisions. If a conservator of my person should need to be appointed, I designate be appointed my conservator.

If is unwilling or unable to serve as my conservator, I designate, No bond shall be required of either of them in any jurisdiction.

I hereby make this anatomical gift, if medically acceptable, to take effect upon my death.

I give: (check one)

... (1) any needed organs or parts

... (2) only the following organs or parts

to be donated for: (check one)

(1) any of the purposes stated in subsection (a) of section 19a-279f of the general statutes

(2) these limited purposes These requests, appointments, and designations are made after careful reflection, while I am of sound mind. Any party receiving a duly executed copy or facsimile of this document may rely upon it unless such party has received actual notice of my revocation of it.

Date, 20

...L.S.

This document was signed in our presence by the author of this document, who appeared to be eighteen years of age or older, of sound mind and able to understand the nature and consequences of health care decisions at the time this document was signed. The author appeared to be under no improper influence. We have subscribed this document in the author's presence and at the author's request and in the presence of each other.

(Witness) (Number, Street) (City, State, Zip Code)

(Witness) (Number, Street) (City, State, Zip Code)

STATE OF CONNECTICUT

COUNTY OF

)))ss.

We, the subscribing witnesses, being duly sworn, say that we witnessed the execution of these health care instructions, the appointments of a health care agent and an attorney-in-fact, the designation of a conservator for future incapacity and a document of anatomical gift by the author of this document; that the author subscribed, published and declared the same to be the author's instructions, appointments and designation in our presence; that we thereafter subscribed the document as witnesses in the author's presence, at the author's request, and in the presence of each other; that at the time of the execution of said document the author appeared to us to be eighteen years of age or older, of sound mind, able to understand the nature and consequences of said document, and under no improper influence, and we make this affidavit at the author's request this day of 20...

(Witness)

(Witness)

Subscribed and sworn to before me this day of 20..

....

Commissioner of the Superior Court

Notary Public

My commission expires:

(Print or type name of all persons signing under all signatures)

(P.A. 93-407, S. 1

Authors' Curriculum Vitae

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Background: I am nearly 81 years old, a Connecticut native, a WW II veteran, Yale University '45 (B.S.), and Harvard Law School '51 (J.D.).

I was an active lawyer for nearly 50 years, in my early years as a prosecutor for the Department of Justice, then representing a variety of private clients, including doctors and hospitals, in diverse ways. I have a continuing association with Yale's Bioethics Center. I have had an interest and have been involved in "the right to hasten death" and "end-of-life care" issues since the late 1970s.

Allan Brandt MD (allan-brandt@sbcglobal.net)

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203 283-1931

Background: I am 84 years old. A pioneer in Emergency Medical Systems and Life Support now dedicated to End of Life Issues.

Amherst College BA '45, MA (Biology) '46, Yale University '51 (M.D.), Southern CT State University: BS (Studio Arts) 1994

Affiliate Faculty, Computer Science Department, Southern Connecticut State University 1996 - 2003.

Connecticut: Community Physician - 17 yrs.

Milford Hospital: Chief of Medical Staff

Director of Emergency Medical Services (EMS) - 17 yrs. more.

Chairman Milford EMS Council - 2 years

President of Connecticut Emergency Physicians

Member Governor's EMS Council

Chairman of State Task Force to set State EMS Standards

Member American College of Emergency Physicians

Member of American Heart Association Advanced Life Support Committee

Created Basic Life Support Course for High School Students, nationally.