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Advance Directives, Autonomy, and Unintended Death¹
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Living wills typically have two defects. First, most living wills fail to enable people to effectively avoid unwanted medical intervention. Second, most living wills have the potential of ending your life in ways you never intended, years before you had to die. Policy issues surrounding advance directives often seem pretty obvious and simple, when in fact they are demonically complicated and difficult. Partly as a consequence, living wills and other advance directives tend to be ill-crafted, vague, and confusing to lay people, lawyers, and the medical professionals who implement them--though usually nobody is aware of the confusion until a crisis, if then. People generally do not understand the implications of the advance directives they sign, or, for that matter, create.

Philosophers and others with the critical skills to recognize the inadequacies of most living wills seldom give them careful attention. Perhaps this is because advance directives are thought to represent a welcome protection of individual autonomy--something to be supported, even promulgated, not criticized. Certainly living wills are being sold aggressively to the public: I have attended church meetings where well-intentioned doctors peddled truly frightening instruments, urging the audience to

sign "before you go home." Bill and Hillary Clinton are asking Americans to sign living wills. The national organization "Choice In Dying" hopes to persuade 1,000,000 people to sign living wills in 1994. For better or worse, advance directives are the wave of the future. But if that future is to be better than worse, philosophers had better give such instruments a critical going over, before millions of innocents sign on the dotted line.

Consider, as a case in point, the living will published in the American Philosophical Association Newsletter on Philosophy and Medicine (Fall 1990), an effort of the Midwest Bioethics Center and the Kansas City Metropolitan Bar Association, submitted by Joan D. Killion of Midwest Bioethics Center, who writes: "You may make as many copies of the document found on the next two pages as you would like to share with others."² The APA Newsletter has published a full-page copy of the will, to facilitate its widespread distribution. Editor Rosamond Rhodes writes: "This document, reproduced at the end of the article, satisfies the stringent requirements of both Missouri and Kansas and also allows each will writer to customize the document to meet personal needs."³ In the first part of this paper, I propose that we subject the Midwest Bioethics Center Living Will (as I will call it) to the scrutiny we would give a contract concerning a used car, not to mention a matter of life and death. I believe you will find the exercise illuminating, far more than any abstract discussion could be.

Of course, advance directives do not operate in a Platonic

realm; they need to be evaluated against the background of the institutions in which they will actually be implemented. Yet this is almost never done. For example, few philosophers can imagine the incompetence and confusion concerning advance directives in many nursing homes, though it is in nursing homes that many advance directives will be implemented. In the second part of this paper, I want to relate some of my experiences in trying to protect the life of a severely disabled woman, my sister, who has lived in hospitals and nursing homes for the last twenty years. Here I will consider both living wills and advance directives concerning resuscitation. Again, I believe you will find the story more illuminating than any abstract discussion could be. In the third part, I will consider a recent alternative to traditional living wills, namely, advance directives establishing durable power of attorney for health care.

I

The MBC Living Will consists of a standard living will declaration followed, on the second page, by Optional Additional Instructions so that we can "customize" the document to meet our personal needs. The substance of the living will declaration is this:

If at any time I should have an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized, and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, and I am unable to

participate in decisions regarding my medical treatment, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort.⁴

This statement invites some obvious questions. First, if two physicians must "certify" that I am in a terminal condition, how are they to do it? Doctors have never been asked to "certify" such things; naturally they may be concerned about legal liability. The will provides no hint of a suitable procedure or instrument, which is an impediment to its being implemented. Also, the statement is sufficiently convoluted grammatically to make it unclear what it is both physicians must certify. It appears that both must certify that my death will occur whether or not life-sustaining procedures are utilized (unfortunately, this is formulated so that it is satisfied vacuously for all people at all times). But must both physicians (or, for that matter, anyone) "certify" that I am "unable to participate in decisions regarding my medical treatment"? This constitutes a determination of mental incompetence, a judgement that has been reserved to the courts. How are they to "certify" that? Would it involve a formal statement? Must both doctors "certify" that the application of life-sustaining treatment would serve "only to artificially prolong the dying process"? What does that mean, anyway? The attending physician, who must explain to a colleague what to certify and how to certify it before the will can be implemented, is left wholly at sea. Indeed, the MBC Living Will may result in your continued futile treatment while the attending

physician, who otherwise would have let you die on the traditional ground that doctors have no duty to impose futile therapies on patients who cannot consent, hunts about for a willing colleague and legal advice so that he can without liability satisfy the conditions of the will.

Second and more serious, what is the meaning of the operative term "terminal condition"? Remarkably, the MBC Living Will is wholly silent on this point. Tabor's Cyclopedic Medical Dictionary defines "terminal illness" as "illness that because of its nature can be expected to cause the patient to die; usually a chronic disease for which there is no known cure."⁵ This certainly captures what many people have in mind when they sign a living will--for instance, most would agree that acquired immune deficiency syndrome is a terminal condition, for it is bound sooner or later to terminate your life. On this reading, the MBC Living Will could end your life years before the "terminal condition" would have killed you. A different account: The Long Term Care Facility Ombudsman of a western state recently sent me the third draft of a new brochure explaining living wills, prepared by an attorney, the ombudsman, and several medical professionals, which defined "terminal condition" as "any injury, disease, or illness from which you will not recover." On this account, it is not required that a terminal condition be life-threatening or even serious. Rheumatism is included, along with chronic allergies. This is an instance of the confusion that surrounds the operative terms in living wills: lawyers and

medical professionals are sure they know what the terms mean, though they often give substantially different (not to mention hair raising) accounts.

Joan Killion kindly informed me in a telephone conversation that in Kansas and Missouri "terminal condition" is legally defined as "a condition where death will occur in a short period of time whether or not life-sustaining procedures are given." The law does not specify how short the period of time must be. (Consequently a physician nervous about implementing the will need only judge that the time remaining may not be sufficiently short.) However she cautioned me that the term (and consequently the MBC Living Will) might well have a different meaning elsewhere in the country. Then why distribute the MBC Living Will nationwide without defining the operative term? Signing this living will may have different consequences in different states, and the meaning of the document may shift over time. If legislation defining "terminal condition" is passed in your state and then modified later the will may have one meaning when you sign it and a very different meaning when it is implemented. Equally important: Without a definition of "terminal condition" in the living will itself, most signers will only vaguely understand the circumstances in which the will applies (or they will have a significantly mistaken idea), though they probably will be unaware of this. And it is my experience that physicians, family members, and clergy with whom they may discuss the document will be no better off. It is improbable that anyone

involved will be acquainted with the local legal definition of "terminal condition," if there is one. Indeed, it will never occur to most signers that there is a question or problem here at all. And the two physicians who must "certify" that the patient is in a "terminal condition" before the will can be implemented, will probably themselves not be clear on what the term means, not to mention what the signer had in mind when she signed the document years before, perhaps in another state. Sherrill Whately, R.N., who works in an ICU in Tucson, wrote in correspondence:

It is very difficult to make the term "terminal" stick: it is frequently not applied due to vagueness. I have seen many people with living wills die on ventilators against their will due to the vagueness of the term "terminal." They feel misled...

It is a serious and obvious defect of the MBC Living Will that there is no account at all of the operative term.

Indeed, I believe the term "terminal condition" cannot be defined to meet the purposes of living wills. And the problem iterates for the second operative term in the MBC Living Will, "life-sustaining treatment," which is also unexplained. Consider California's newest amended Living Will statute, the Keene Natural Death Act (1991), which gives these definitions:

"Terminal condition" means an incurable and irreversible condition that, without the administration of life-sustaining treatment will, within reasonable medical judgement, result in death within a relatively short time.⁶

"Life-sustaining treatment" means any medical procedure or intervention that, when administered to a qualified patient, will serve only to prolong the process of dying or an irreversible coma or persistent vegetative state.⁷

"Qualified patient" means a patient 18 or more years of age who

has executed a declaration and who has been diagnosed and certified in writing by the attending physician and a second physician who has examined the patient to be in a terminal condition or a permanent unconscious condition.⁸

Note that "terminal condition" is defined in terms of "life-sustaining treatment," which is defined in terms of "qualified patient," which is defined in terms of "terminal condition." The definitions move in a circle. Further, the critical phrase "relatively short time" is virtually meaningless. Relative to what? (The Hastings Center suggests that a "relatively short time" might be defined as one year.⁹) The California statute leaves the matter wholly to the doctor's discretion.¹⁰ Old age would qualify.¹¹ Worse, the definition of "terminal condition" is incoherent, given a plain reading of the law, for it implies that there may be treatments available that will preserve the life of a terminally ill person for more than a "relatively short time," that is, in plain English, for a long time, perhaps for years. But a treatment that preserves someone's life for a long time does not serve "only to prolong the process of dying," if that phrase has any clear sense, so it is not "life-sustaining treatment," which is what the statute calls it. Indeed, the existence of such treatment implies that the terminal condition is "reversible," or at least that its progress can be slowed markedly, which for the purposes of a living will should amount to the same thing.

The deep problem is that if we take the phrases "without the administration of life-sustaining treatment" and "relatively short time" out of the definition, so that a terminal condition

must kill you quickly no matter what the doctors do, then you will not be in a terminal condition if you can be kept alive a long time on a respirator, say. So the will cannot be implemented under the circumstances for which it was designed. To do its work, the will must allow that you can be in a terminal condition even though your life can be preserved for a long time by measures you choose in advance to forego. But measures that preserve your life for a long time do not "serve only to prolong the dying process," if that phrase has any clear sense. So they are not "life-sustaining treatments." It follows that someone who can be kept alive for a long time on a respirator is not terminally ill, according to the California statute, for his life can be preserved a long time without resorting to "life-sustaining treatments." Again the will cannot be implemented.

The only escape from this dilemma is to broaden the range of "life-sustaining treatments." For example, the Hastings Center defines "life-sustaining treatment" as "any medical intervention that is administered to a patient in order to prolong life and delay death," which captures what most people think the term means.¹² Chemotherapy, insulin, dialysis, blood transfusions, intravenous food and water are life-sustaining treatments. The President's Commission for the Study of Ethical Problems in Medicine writes:

"Life-sustaining treatment," as used here, encompasses all health care intervention that has the effect of increasing the lifespan of the patient, including physical therapy, nursing support for activities of daily living, and special feeding procedures, provided that one effect of the treatment is to prolong the patient's life.¹³

But California cannot count all of these as "life-sustaining treatments," obviously. Too many conditions will qualify as terminal (e.g., kidney disease where death can be forestalled for a decade by dialysis, metastatic cancers where life can be prolonged for many years by intermittent chemotherapy); and it is unlikely that a person who signs a living will intends to forego all of the above if two doctors declare her "terminal" and the attending physician thinks that she "can no longer make decisions regarding her medical treatment"--another matter the statute leaves wholly to the physician's discretion.¹⁴

The upshot is this: If the California statute is to be implemented under the circumstances for which it was designed, without being overly broad, there must be a proper subset of medical treatments and interventions that can preserve life for a long time but, which, nonetheless, "serve only to prolong the dying process." These are the class of "life-sustaining treatments." But now the notion of a treatment that "serves only to prolong the dying process" is unconstrained, indeed, it has no clear sense. In fact, what the statute amounts to is this: if you are in a condition that will probably cause your death sooner or later (unless something else kills you first) and the attending physician believes your life is not worth preserving, then you are in a "terminal condition," and any medical intervention that prolongs your life, even for years, is "life-sustaining treatment," including antibiotics, dialysis, and artificial hydration. If, under the same conditions, the attending physician

thinks your life is worth preserving, then medical intervention that prolongs your life is not "life-sustaining treatment" and you are not in a "terminal condition." In general, signing a living will does not preserve your autonomy; rather, it places you entirely at the mercy of doctors, who decide whether you are competent to participate in treatment decisions, how long a "relatively short time" is, whether you are "terminally ill," and what counts as the "life-sustaining treatment" to be foregone. As Thomas J. Marzen observes: "Execution of a declaration is more of an act of faith than an act of will--an essentially symbolic gesture that effectively delegates decisions on all crucial matters to the discretion of an attending physician."¹⁵

Matters get worse on the second page of the MBC Living Will where Optional Additional Instructions are provided to enable us to customize the will to meet our personal needs. Of course, many signers will stop at the declaration on the first page, satisfied that it expresses their wishes. The Optional Additional Instructions begin:

The following (or photocopy thereof) is a statement of my treatment wishes if I lack the capacity to make or communicate decisions regarding my medical treatment and there is no reasonable expectation that I will regain a meaningful quality of life.

I direct all life-sustaining procedures be withheld or withdrawn if I have:

a terminal condition, or

a condition, disease or injury without hope of significant recovery, or

extreme mental deterioration, or

The MBC Living Will states that all "life-sustaining procedures" are to be withheld or withdrawn under any of these circumstances unless the signer draws a line through and adds her initials. (As "life-sustaining procedures" can now be withheld or withdrawn even when I am not in the process of dying, the phrase cannot mean "procedure that serves only to prolong the dying process," but "any procedure that sustains or prolongs life.") The direction to withdraw or withhold all life-sustaining procedures becomes operative when two conditions are satisfied: I lack the capacity to make or communicate decisions regarding my medical treatment, and there is no reasonable expectation that I will regain a "meaningful quality of life." But this statement is extraordinarily and dangerously unclear, for two reasons. First, if I lack temporarily the capacity to make or communicate decisions regarding my treatment, is the first condition satisfied? Or is it required that the incapacity be judged something permanent (or at least indefinite)? Suppose I become quadriplegic, and later catch pneumonia so that I am too sick to communicate my decisions. My doctors judge that I will get well enough in a few days to communicate if they give me antibiotics. Otherwise I will die. Should they judge the first condition satisfied and go on to ponder whether quadriplegics have a "meaningful quality of life," or should they judge the first condition unsatisfied and save me? Or suppose a quadriplegic suffers a stroke and cannot communicate, though the doctors judge

that she will probably regain that capacity in a week or so if they keep her on a respirator. Reading the will literally, the first condition is satisfied in both cases. I submit that it is irresponsible in evaluating a document dealing with a matter of life and death, to suppose the implementers will not take it to mean what it literally says. Here the will endangers the autonomy it is designed to protect. But those who sign the statement will not understand this implication; few would sign who did.

Second, the phrase "quality of life" is virtually meaningless, and the expression "meaningful quality of life" is worse. In Clinical Ethics, Jonsen, Siegler, and Winslade observe:

The phrase "quality of life" is frequently heard in clinical discussions about ethical problems. Frequent use has given the phrase neither any precise meaning nor any definite application. It seems an attempt to put a value upon some feature, or collection of features, of human experience. As such it is highly subjective; yet the phrase is often used by someone other than the person who is living the life being evaluated.¹⁷

A good way to destroy public trust in the medical profession is to encourage doctors to make highly subjective decisions, based on an empty phrase, concerning who lives and who dies--an outcome the MBC Living Will invites on a large scale. By what standard can a doctor judge that my life will not regain a "quality" that is "meaningful"? And note that the requirement that at least two physicians agree about any of this has fallen away, though this statement is far stronger than the previous one, potentially directing the withdrawal of all "life-sustaining procedures" in cases where I am not even "terminally ill." Many physicians will not touch this statement with a ten-foot pole,

rendering it ineffective; those undeterred are liable to make judgements the signer might well consider idiosyncratic. (Remember that for many signers the directive will finally be implemented, perhaps scores of years hence, by a physician they may never even have met.) I recall a neurosurgeon apologizing sincerely to a young woman's family for saving her life; now she would be a cripple, he said. More than a few doctors believe mild retardation in an infant deprives his life of sufficient "meaning" to warrant surgery to correct intestinal blockage. Many doctors automatically consider any nursing home resident terminally ill, mentally incompetent, and lacking a "meaningful quality of life." (Note that the standard living will declaration is triggered under these circumstances.) I once saw a respected internist no-code a 41-year-old, healthy, manifestly happy disabled woman residing in a nursing home, simply because she was there--without informing anyone he had done so.¹⁸ Any seriously injured young person, temporarily unable to communicate, who will be significantly disabled after the doctors save him, can lose his life as a consequence of signing this will. Any elderly or disabled person in a nursing home will be at risk. Few who sign will understand the implications.

The framers of the will provide an additional statement in the middle of page 2:

A meaningful quality of life means to me that: (This does not need to be filled in for the instructions to be valid.)¹⁹

Sadly, the emphasis is in the original. Those undiscouraged who go on to the unnecessary bother of completing this entry, must wrestle without guidelines with "meaningful quality of life," a phrase with "neither precise meaning nor definite application." Naturally much of what is written will share the defect; a good deal will be dangerously broad, vague, and confused. Many will not understand the lethal implications of what they have written.

Matters get worse still. Remember the Optional Additional Instructions continued:

I direct all life-sustaining procedures be withheld or withdrawn if I have:

a terminal condition

This term is undefined in the MBC Living Will, and I hardly need repeat that it may have different meanings in different times and places, as well as for different doctors and patients.

a condition, disease, or injury without hope of significant recovery

Note that the condition, disease, or injury without hope of significant recovery need not be life threatening or even serious. Blindness qualifies, along with arthritis and chronic eczema. Few who sign will realize this. And remember, all life-sustaining procedures (e.g., antibiotics, insulin, blood transfusions) are directed to be withheld or withdrawn under this circumstance unless Uncle Henry takes the trouble to draw a line

through it and sign his initials. The MBC Living Will errs grossly on the side of death. Let this one get by you and you may be denied life-saving surgery if you are too sick to communicate, you are permanently blind or disabled, and a doctor makes an idiosyncratic judgement about the "quality" of your life.

extreme mental deterioration

Note that the mental deterioration need not be permanent or irreversible for this condition to be satisfied. Your mental condition "deteriorates" just in case it "becomes worse." What gets bad can get better, so there can be temporary extreme mental deterioration. The term "extreme" is vague and subjective (is loss of short-term memory plus all comprehension of dates, times, and numbers "extreme"?), and "mental deterioration" is sufficiently general to include psychosis and the immediate aftermath of a stroke.

The MBC Living Will is dangerously defective in ways that few who sign it will recognize. But I believe it is better than most of the living wills now being distributed zealously. I propose that we resist the popular contention that dangerous advance directives are the price of enabling people to avoid unwanted medical intervention. Directives are dangerous because they are nebulous and confused, and a muddled directive will not effectively enable you to avoid unwanted intervention; indeed, it can have the opposite effect. I observed earlier, however, that

advance directives must be evaluated against the background of the institutions in which they will actually be implemented. Living wills may be alarming, but they represent only the surface of a far more dangerous situation, invisible to most signers. What will happen to the advance directive you sign?

II

In 1974 my sister Michele, the mother of a two-year-old, suffered a stroke due to an aneurism, which left her permanently brain damaged, quadriplegic, and barely able to speak. She was twenty-eight. Michele was twice resuscitated after the stroke and she was in a persistent vegetative state for six months, the doctors insisting that she would never talk again--until she began talking again. Relatives described my sister's condition as "a fate worse than death," but this was not so, for over the next two years Michele reemerged as a feisty, funny, indomitable woman, sans numbers and dates, her short-term memory impaired, unable to read or write, yet more than ever before herself. When her husband divorced her and remarried, Michele grieved for months--until one day I found her cheerful and smiling. "Plenty of fish!" Michele said. When he refused to allow her visitation with her daughter, maintaining that Michele was a vegetable, she went to court, singing in her wheelchair on the witness stand when she could not speak, defeating him. "You've changed a lot

since the stroke" I once observed. "Better!" Michele responded. "How better?" "Grew up!"

Michele gave me durable power of attorney to deal with her affairs, with the understanding that I would do what she wanted. In that capacity, I stayed in close touch with her nursing home and with her physician. In 1986 I received a Fulbright to teach in India, and I visited Michele to say goodbye. She had formed a close friendship with another resident, a retired attorney, but she drew the line at marriage. "Too tall!" Michele complained. "Not Jewish!" "Of course, you will save her if anything goes wrong," I told the charge nurse on Michele's floor on my way out of the facility. "We can't do that," the brave nurse said, and she showed me the DNR order Michele's doctor had put in her chart six months before, without informing us. I had ordered him explicitly the previous year to resuscitate Michele if ever it became necessary. It transpired that the medical director of the facility had phoned the residents' attending physicians, asking them to record a decision about resuscitation in each resident's chart. The doctors had come in and no-coded everybody, without consulting or informing the residents or their families. (As I observed earlier, for many physicians it is a foregone conclusion that the life of a nursing home resident is not worth preserving.) The charge nurse understood perfectly the force of the no-code: if something went seriously wrong, she would stand aside and let Michele die.

I tore the code out of the chart. The social service worker

happened to be standing near the nurse's station. Social service workers typically have the job of discussing resuscitation with incoming residents, and helping them to sign an advance directive. "We don't have to worry about resuscitation here," she explained to me. "We don't have the facilities to do that sort of thing." "You mean the nurses don't know CPR, and you don't have oxygen?" I asked. The social service worker became visibly confused and perplexed. She looked at the nurse questioningly. It became plain that she did not know what the word "resuscitation" means. This level of incompetence may be difficult to believe, but it is hardly uncommon. The average tenure of a social service worker in a nursing home is six months.²⁰ The job is demanding and poorly paid; and it often tends to attract young college graduates (many of whom have no background in social work) who are not career oriented.²¹ In rural areas the college-degree requirement can be waived to allow the position to be filled. Some social service workers in nursing homes--especially more mature women--are very good. Others have trouble writing sentences; functional illiteracy is not uncommon even among American college graduates. Social service workers in nursing homes especially do not understand advance directives, and they often have little conception of the gravity of the decisions involved. Some are zealous, inventing their own advance directives for all incoming residents to sign, the principal words misspelled. Others repeatedly question healthy young residents who have opted for resuscitation, "to see if they have

changed their minds." If you enter a nursing home, the social service worker will collect your living will.

I wheeled Michele to the nursing home director's office, who defended the placing of the DNR order in Michele's chart. "We can put any order we want in anyone's chart," she insisted. "There is no obligation to ask or inform anyone. The onus is on the family to make their wishes known. Till then I can do as I choose." Later I saw the director accost a resident, asking bluntly: "Do you want to be resuscitated?" The resident had no idea what the question meant. The average tenure of a nursing home director is one year; having shepherded my sister through five facilities in twenty years, I have known quite a few. Few understand advance directives well, or resuscitation policy, which they often set for their facility, assisted by the social service worker. Generally, in the last decade in nursing homes, the job of raising the resuscitation question and setting policy has tended to pass from nurses and doctors to non-medical personnel.

In 1989, Michele's facility was acquired by a national chain.²² The central office in Florida adopted an advance directive for all of its fifty-three facilities, to be signed by every resident on admission. I found the same directive in use in other chains with hundreds of facilities. The social service worker in Michele's nursing home posted me a copy, requesting that I sign it, so she could "send it along to the doctor."

RESUSCITATION ORDERS

In the event that my physical condition declines to the point

they will be no-coded as soon as the attending physician posts it back to the social service worker, many years before they are in a terminal condition. In fact, most people who enter a nursing home are not terminally ill; many are not terribly old, some are in their twenties--you go to a nursing home when you need full-time nursing care. (There are intelligent, charming old people in nursing homes, there is quite a bit of sex, people fall in love: for many nursing home residents life goes on.) Once the no code is in the resident's chart, it is unlikely she will ever discover it. Hence the no code may end her life years before she becomes terminally ill; for if she suffers arrest as a result of being given the wrong medication, an electric shock, drowning in the bath, choking, or any of the reasons any of us might stop breathing at anytime, the nurses are under orders to stand aside and let her die. Further, as a matter of policy, the nursing staff will try aggressively to transfer the no code to any hospital the resident ever enters for any reason (e.g., surgery to remove an impacted wisdom tooth), so that--if they succeed--the hospital staff will let her die if there is an accident with anaesthetic, say, or cardiac arrest due to an embolism.

In general, when you ask people who are not terminally ill to sign a resuscitation order, no matter how it is worded they assume that it will go into effect only when they are dying. The alternative never occurs to them. I mentioned this to the wife of a philosophy professor in Colorado, who went to her mother's facility and found that her mother had been no coded for two

years: she never dreamed when she signed the form on admission that her mother would be no coded before she was dying. As I write, I believe that thousands of nursing home residents have DNR orders in their charts without knowing or wanting it, because they did not understand the implications of the advance directive they were requested to sign--along with numerous other forms--on admission.

Note that the form gives no indication that the resident or responsible party know what the resuscitation order is about, have considered the risks and benefits of CPR, or are aware of the resident's prognosis and the consequences of CPR for someone in his particular condition. The social service worker has no medical training. The form is completed by the resident on admission, without medical counsel, then forwarded to the attending physician, who functions as a rubber stamp. Consequently the signing of the order cannot constitute informed consent (note that most living wills are also signed without medical counsel). Also, the policy is coercive. Signing the form is likely to be perceived as a condition of admission. The family member who insists on thinking things over is apt to get a letter saying: "We need you to fill out this form." In my own case, visits to my sister became difficult because the nurses would request me to sign the order "before you leave." Note too that the order is all or nothing, allowing the resident only two options: to accept or to decline all CPR, regardless of the circumstances. And there is no provision for periodic review.

This can lead to the futile resuscitation of the dying against their wishes. Mr. Smith must make a decision upon admission; as he is in good health, he requests that the staff attempt CPR. Later he becomes incompetent, and later still terminally ill. When he finally suffers arrest due to the primary illness, the staff, confronted with Mr. Smith's order (which binds him, his family, and all legal and personal representatives until he revokes it in writing) resuscitates him repeatedly, something he never would have wanted--this because there was no way he could express the conditional request that he be resuscitated except in the last stages of a terminal illness.

This policy is not part of an evil scheme to cut costs by allowing the elderly and the disabled to asphyxiate at the earliest opportunity; rather, it flows from confusion on the part of the people who created it. For example, the resuscitation policy statement for the chain (which the social service worker is supposed to review with the resident on admission) defines "resuscitation" as "an extraordinary, 'heroic' means employed to maintain the life of a patient." Note that vague and subjective terms like "extraordinary" and "heroic" are likely to prejudice the resident against choosing resuscitation. Worse, the crucial requirement is omitted that resuscitation must aim at reviving someone who has suffered cardiac or pulmonary arrest. Placing an alert resident who has suffered renal failure on dialysis is "resuscitation" by this definition, if the measure is considered "extraordinary" or "heroic." The definition, which appears

prominently in the policy statement, potentially invites the removal of anything that preserves a resident's life, before she suffers cardiac or pulmonary arrest, if she has signed a DNR order.

In fact, nursing homes and hospitals are quite confused about what such an order entails. In a 1993 article in American Journal of Critical Care, Celine Marsden, R.N. writes: "In addition to differing interpretations of the meaning of CPR/DNR, nurses and physicians are often confused about what care is to be provided for patients with a written DNR order."²³ Mildred Simmons, the Long-Term Care Facility Director for the Colorado Department of Health, at a meeting in 1989 called to discuss these issues, told me that a wide range of "life-preserving means" were being withheld in Colorado facilities from residents who had opted against CPR. Some had been allowed to choke to death; in some facilities, she said, residents had been denied food and water. Such stories can make the papers when the victim is newsworthy. I quote from a 1993 newspaper account of the death of an Indian woman, Mary Jo Estep, a survivor of one of the West's last Indian massacres.

The story begins with a medication mix-up the morning of Dec. 19 at Good Samaritan Health Care Center in Yakima. Estep, 82, was accidentally given three doses of prescription medicine intended for another resident.

Although the error was discovered less than a half hour later, she would never be told the severity of the accident, nor be given the option of seeking emergency treatment. Nursing home officials say Estep's attending physician ... ordered no corrective measures because of the woman's advance directive barring heroic measures to keep her alive. In medical jargon, she was a "no code" patient.

Estep had remained coherent and alert during the first eight hours following the medication error,... But by late afternoon her heart rate and pulse began falling. Sixteen hours after swallowing the wrong pills, Estep was pronounced dead.

"It really disturbs me that they took her like that," said one of Estep's closest friends,... "She was very well, very alert, and you can't tell me that being 'no code' means being left to die like that."²⁴

Now we can address the question: What will happen to your living will after you sign it? The Patient Self-Determination Act of 1990 requires every hospital and nursing home to ask every patient at admission if they want to fill out a living will. (Note that the sick patient can hardly consider the advance directive intelligently at check-in, another reason why signing it is not informed consent.) The hospital or nursing home must also ask if you already have a living will, and record it in your medical record. There the advance directive is liable to function as, or be translated directly into, a DNR order, even though you are neither incompetent nor terminally ill. Doctors and nurses cannot be relied upon to distinguish living wills from DNR orders, whether you are in a hospital or a nursing home. (In nursing homes, as I mentioned earlier, there is the risk that the directive will be triggered simply by your being there, so that you will be denied all "life-sustaining treatment.") In an article in the magazine Nursing Spectrum, Diane Majka-Grandstrom, R.N. writes:

A retired nurse was admitted to the hospital for steroid therapy for multiple sclerosis. Aware of the Patient Self-Determination Act (PSDA), she brought along her living will. Her physician, upon reading it, wrote a do not resuscitate order on her chart.

If you find nothing unusual in this scenario, you may be one of many who confuse living wills with DNR orders. The nurse did, in fact, state in her living will that she did not want CPR or a long list of other treatments. However, she knew that the will would only go into effect if she became terminally ill and unable to communicate, or permanently unconscious. Multiple sclerosis is not a terminal condition. And the nurse was communicating quite well.²⁵

"Why do people confuse living wills with DNR orders?" Majka-Grandstrom asks. "As a result of the PSDA, health care professionals are informing consumers about their right to make advance directives, but the general public and health care professionals are both unclear or uninformed about the timing and process of advance directives."²⁶

This confusion can have lethal consequences. I quote from a recent letter by Phyllis J. Robb, of Fort Wayne, Indiana, to The American Medical Association News:

My mother, at 73 and in excellent health, entered the hospital for her second hip replacement. After six days, she left the hospital and entered a transitional care unit. On entry she was given a standard living will for her consideration. She signed it, not adding any special instructions; she did not take it seriously enough to even mention to us.

In our state, the living will takes effect only if the person is terminally ill and unable to communicate. It is a short simple form, and the language is clear. Regardless, a staff person wrote on mother's record "no code, patient's request." The family was not informed.

On the 11th day after surgery, mother suffered cardiac arrest due to an embolism. The staff did not call a doctor or attempt to treat her in any way; they did not wish to "go against her wishes." They stayed by her side for 20 minutes while she died. My reaction was shock and disbelief.²⁷

Robb, formerly a strong supporter of living wills, concludes that she would not sign a living will or allow information about her wishes to be entered into a facility's records. She writes: "Now

I know that, to many professionals, a patient who has a living will 'wants to die.' All the fine points elude them."²⁸

The bottom line, then, is that advance directives are often dangerously confused, even when they least appear to be, and those who implement them are often more so, though they usually do not know it. Consequently signing a living will or a resuscitation order is imprudent, because--at the very least--you risk putting yourself at the mercy of people who do not know what it means. Given the procedural chaos, incompetence, and high turnover endemic to many of the institutions in which advance directives are implemented, the situation is unlikely to improve enough to make signing one more than a fool's gamble. You risk losing your life, and the directive does not effectively or reliably enable you to determine your future treatment. Philosophical questions aside, why die stupidly? There has to be a better way.

III

In recent years many states have passed laws enabling people to designate a proxy to supervise treatment in case they become incompetent. This is largely the result of a three-pronged effort by Choice In Dying to establish in each state a living will statute, a durable power of attorney for health care statute, and an automatic surrogacy statute. The last law establishes a pecking order of relatives and friends whom a doctor must ask to

represent an incompetent patient who has never signed an advance directive. (If no one can be found, the job may devolve to the attending physician.) In some states, Oregon for instance, this representative can remove all "life sustaining treatment" from an "incompetent" patient who is merely in a "terminal condition," though he has never expressed a wish that this be done; and the surrogate may be a complete stranger.²⁹ Obviously, automatic surrogacy provides a powerful incentive to sign an advance directive; at the very least, most people can think of family members whom they would not want directing their medical care.

I have talked to lawyers who predict that directives designating a health care representative will replace living wills, which are on their way out. This is unlikely, for several reasons. First, living wills are easy to sign and, as I observed earlier, they are being very widely distributed. Choice In Dying has already given out between 15 and 20 million advance directives, most of them living wills. The organization is now distributing both kinds of directives in every state.³⁰ Second, many people will sign a living will because they cannot find a suitable health care representative. Third, the durable power of attorney is inadequate unless it is combined with another advance directive. The designated representative may become incapacitated before the signer; further, even if she signs the document (as she must in some states), she can resign whenever she likes by writing a letter saying so. Then the automatic surrogacy statute is activated and a proxy will be found who may be entirely

ignorant of the signer's wishes. Consequently, many people will also sign a living will in order to instruct and constrain the replacement (or, for that matter, the original proxy), who is bound by law to honor such declarations. In fact, this may create a potential conflict between the two advance directives. As the living will is a more specific document expressing the patient's personal instructions to the doctor, and as living will statutes require the attending physician to implement the will regardless of what other parties say, it may supersede the durable power of attorney.

A popular solution is to include directions for the health care representative in the document that creates the durable power of attorney for health care. Then, if the representative quits or is incapacitated, the instructions bind her replacement. (If no replacement can be found except the attending physician, the durable power of attorney degrades into a de facto living will.) This hybrid document is, in effect, a living will directed at a proxy, who instructs the attending physician. This preserves some of the chief dangers of living wills. Most notably, someone in the future must implement a nebulous and dangerously confused advance directive. Some of the written instructions may be virtually meaningless; others may have unintended lethal consequences upon which the representative will act. Most family members have far less grasp of medical issues and terminology than do doctors, and little practical experience in medical crises. Also, the proxy is more likely to become distraught.

Consequently, representatives will often be even less capable than physicians of rationally interpreting an advance directive. Doctors tell stories in which, say, a 70-year-old woman has a stroke and is placed on a respirator, an irate family member arrives flapping a living will and demanding that life support be withdrawn, the doctor refuses, the woman recovers completely and says she never dreamed that the will might have this sort of result. When the family member is the proxy, whose duty it is to implement the advance directive, it will be far more difficult for the physician to refuse. Also, as every medical facility one ever enters will record the durable power of attorney, there is a danger that the "living will" declaration and instructions intended for the proxy will sooner or later function in the minds of staff as a DNR order. It can be difficult to distinguish a hybrid advance directive from a traditional living will, and, as Ms. Robb observes "all the fine points elude them."

Of course, finding an intelligent, informed, and assertive individual to represent you if you become incompetent is a very good idea. Indeed, find two or more if you can, and designate an order of succession. By all means discuss your preferences with this person, but saddling her with a living will or a hybrid directive that it will be her first duty to implement perhaps decades hence is a mistake. There is little need to worry that, without a living will, she will lack sufficient authority to refuse futile treatment when you are dying. It is unlikely that any physician will refuse a legal proxy's request that futile or

painful treatment be withdrawn from a plainly incompetent patient; and the proxy can fire any doctor. (I could no-code my sister today, despite the fact that she is still young, healthy, and competent; her attending physician would not bat an eye.³¹) To the contrary, your representative may spend her time demanding second opinions, firing incompetent or uncaring physicians, checking your chart for negligent DNR orders, and generally fighting to preserve your life and health.

If you are in a PVS or an "irreversible coma," several states may not allow a proxy to withdraw life support unless he produces "clear and convincing evidence" that you would want this done.³² Many people sign living wills partly because they fear these conditions, hence it is worth noting that the prospect of ending up in either state is statistically remote: you probably have more to fear from signing a living will. People so diagnosed sometimes regain consciousness; if you choose not to wager that you will be one of them, give a signed, witnessed, and notarized statement to your proxy saying so.³³ Include the instruction that the affidavit must remain in his possession and not be given to any facility. Also, as your proxy may come under pressure from doctors and administrators to withdraw treatment, providing him a signed and notarized list of prohibitions will help him to resist. For example, if you do not want artificial hydration withdrawn, or you do not want to be no coded before you are dying, a statement prohibiting him from doing so would be helpful. As active euthanasia may be legal before you die, you

may choose to prohibit your proxy from exercising that right in your behalf. Finally, if you cannot find a suitable proxy and you feel you must have an advance directive, draft a document that begins "I want all treatment, except...." Then enumerate as clearly as you can, with the help of your attending physician, the treatments you do not want and the circumstances in which you do not want them. The positive statement at the beginning may help prevent you from being perceived as someone who "wants to die."

To conclude: instruments concerning matters of life and death should all be subjected to the sort of critical review we have given the MBC Living Will, resuscitation orders, and directives creating a durable power of attorney for health care. Unfortunately this is seldom done. Philosophers have the critical skills to recognize the defects of these directives, if only we will use them. When next you see an advance directive, I appeal to you to read it with care. If it is defective, bring this to the attention of the framers and to those who might sign it uncritically. If you do not, you can be certain that no one else will, for almost no one else can. If we lack the wisdom to make us kings, surely philosophers have sufficient technical insight to function as guardians of the elderly and the disabled as our society ages. The life you save may be your own.³⁴

Notes

1. This is a revised and much expanded version of "Living Wills,

Autonomy, and Unintended Death," which appeared in The American Philosophical Association Newsletter on Philosophy and Medicine, (Fall, 1991), Volume 90:3, 41-45. I will not treat in this paper advance directives that give a friend or relative durable power of attorney to direct medical care when the signer becomes incompetent. My concern will be written declarations and instructions that attempt to decline or accept future medical treatment. The strategy of designating someone to take over when I cannot cope seems sufficiently different (and complex) to merit separate consideration. (Note, however, that durable power of attorney directives are sometimes hybrids, including a declaration telling the attorney how to direct future medical treatment: much of my critique of the more traditional advance directives will pertain to these.) It may seem plain that durable power of attorney directives avoid some of the dangers of traditional living wills; however I cannot endorse them until I study them more thoroughly. In my experience, advance directives are seldom what they seem.

2. APA Newsletter on Philosophy and Medicine (Fall, 1990), Volume 90:1, 10.

3. APA Newsletter, 5.

4. APA Newsletter, 11.

5. Tabor's Cyclopedic Medical Dictionary, Editor, Clayton L. Thomas, M.D. (Philadelphia: F.A. Davis, 1989), 1836.
6. California Natural Death Act, Senate Bill No. 980, (1991), chapter 3.9, sec 7186, (j).
7. California Natural Death Act, sec 7186, (d).
8. California Natural Death Act, section 7186, (h).
9. Hastings Center Guidelines On The Termination of Life-Sustaining Treatment and The Dying, (Hastings Center, 1987), 141.
10. California Natural Death Act, section 7190.5, (a) and (b).
11. Nothing in the California Natural Death Act precludes this.
12. Hastings Center Guidelines, 140.
13. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research--Deciding to Forego Life-Sustaining Treatment, (US Government Printing Office, March 1983), 3.
14. The Declaration included in the statute includes the condition that "I am no longer able to make decisions regarding

my medical treatment." California Natural Death Act, sec 7186.5, (b). As far as the statute is concerned, this condition is satisfied if the attending physician thinks it is; and nothing need be recorded anywhere saying that this is what he thinks. The physician is absolved of all liability if he "believes in good faith" that his action "is consistent with this chapter and the desires of the declarant expressed in the declaration."

California Natural Death Act, sec 7190.5, (b).

15. Thomas J. Marzen, J.D. "The 'Uniform Rights of the Terminally Ill Act': A Critical Analysis," in Issues in Law and Medicine, Vol.1, No. 6, (May 1986), 470. This is an excellent critique (which has certainly influenced this paper) of the attempt in 1985 by the National Conference of Commissioners on Uniform State Laws to promote uniformity in state living will statutes.

16. APA Newsletter, 12.

17. Albert R. Jonsen, Mark Siegler, William Winslade, Clinical Ethics, Second Edition, (Macmillan, 1986), 102.

18. My sister, in fact; more about this later.

19. APA Newsletter, 12.

20. This is my own conclusion based on two decades of experience,

confirmed by conversations with Ron Tryon, the present director of my sister's facility, who himself worked for several years as a social service worker in nursing homes. Jobs in nursing homes are hard; the social service worker position is especially so. She must deal with abusive residents, grieving families, resident's financial problems, getting people new false teeth, lots of paper work, and the nursing staff may view her as intruding on their affairs. Mr. Tryon also confirms my observation (stated in the next sentence in the text) that many people in the social service position are there without adequate preparation, primarily because they need a job.

21. Because of the low pay, social workers with MSW degrees are rare in American long-term care facilities.

22. I prefer not to identify the chain because my sister is still in one of its facilities.

23. Celine Marsden, R.N., "'Do Not Resuscitate' Orders and End-Of-Life Care Planning," American Journal of Critical Care, Vol.2, No.2, (1993), 177-179.

24. David Wasson, "'No Code' Nightmare," Yakima Herald-Republic, March 14, 1993, 1.

25. Diane Majka-Grandstrom, R.N., "Living Wills Are Not DNR

Orders,"Nursing Spectrum, April 19, 1993, 6.

26. Diane Majka-Grandstrom, 6.

27. Phyllis J. Robb, "Bitter Lesson On Living Wills," The American Medical Association News, July 12, 1993, 21.

28. Phyllis J. Robb, 21.

29. Oregon Revised Statutes 127.645.

30. Jeff Harrison, a telephone counselor for Choice in Dying, also was kind enough to inform me that his organization estimates that 10% of Americans have signed advance directives. Because durable power of attorney directives are recent, most of these are probably living wills.

31. My durable power of attorney was an arrangement that I concocted with a lawyer in 1976, to protect my sister. It did not involve an advance directive or any mention of mental incompetence. Michele has empowered me to deal with doctors, medical facilities, and government institutions in her behalf. If you spoke Ubangi and only a smattering of English, and you were confined to a medical facility, you might empower a close friend who is fluent in both languages to represent your concerns.

32. Missouri, Illinois, Connecticut, New York, Maine, New Jersey, and Ohio are some of them.

33. A version of Pascal's wager applies to the PVS and to the "irreversible coma." People in such states are not suffering and there remains a possibility that they will wake up, as some do, or that medical advances will enable physicians to help them--the term "irreversible" is, at best, relative to the state of the medical art. Consequently you have everything to win and nothing to lose if you gamble on staying alive: you may wake up and, if you do not, unconscious life is no worse than being dead. Conversely, you have everything to lose and nothing to win if you opt for death. One wrinkle is that you will probably be severely disabled if you recover; however severe disability, while not as good as normalcy, is usually better than being dead. That is what the severely disabled typically say, anyway. We generally do not think that the severely disabled are better off dead; but that judgement should guide decisions about ourselves. (We will all be dead soon enough, in any case, and for a long time.) Consequently it is in our interest to stay alive if we are comatose, the more so the younger we are. This interest is defeasible; for instance, continued unconscious life may be worse than being dead if our financial resources, needed to support our families, will be exhausted. [Note that in most of the famous cases of comatose patients (e.g., Karen Quinlan) insurance or social security paid

the bills.] I submit that anyone who, without considering this sort of argument, signs a directive opting for death if he should become comatose, has not made a reasoned and informed decision. Further, if you are the guardian of a comatose young person, where your first concern must be to do what is in her interest, your duty is clear.

34. I am indebted to Kathi Hamlon, Ed Johnson, Phil Fuselier, M.D., Tom Marzen and Jane Brockmann for helpful conversations, and to Judith Crane and Sherrill Whately, R.N. for their comments.