

Advance Directives in the 1990s

by Joan McIver Gibson

Missouri's handling of the Nancy Cruzan case has prompted renewed interest (some would say anxiety bordering on panic) in executing advance directives such as living wills and health care powers of attorney. Perhaps more than any other recent medical/media event, this legal odyssey has indicated to the general public the importance of expressing preferences and choices well in advance of medical crises. In the period immediately following the United States Supreme Court ruling in *Cruzan*, the Society for the Right to Die reported that it had to hire extra staff to respond to more than 100,000 requests per month it was receiving for information and assistance. In response to an October 1990 article in *Modern Maturity*, the Center for Health Law and Ethics at the University of New Mexico has filled nearly 10,000 requests for its Values History form.

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Common to most inquiries is the question, "How can I insure that my family and my physician follow my wishes?" Common to most advice is the suggestion that the inquirer execute a living will and/or a health care power of attorney (in accordance with state law, if applicable). Less common is concrete and practical instruction on how to identify, express, and document the kind of personal information that will be useful for surrogate decision makers some time in the future. The case of Nancy Cruzan, developing as it has in a state (Missouri) that requires "clear and convincing evidence" of an incapacitated person's prior wishes, highlights the tragic impasse that silence on such subjects may create.

A review of certain features of tradi-

tional advance directives, as well as new (though not statutorily constituted) instruments such as the Medical Directive developed by the Emanuels at Harvard and the Values History we designed at the Center for Health Law and Ethics, may yield insight as to where advance directives are, or should be going in the post-Cruzan era.

Living will laws (now in 41 states plus the District of Columbia) share a focus on medical conditions such as terminal illness or persistent vegetative state, and medical treatments (variously labelled "maintenance medical treatment," "life-saving/life-prolonging/life-sustaining treatment," or "artificial life support"). Health care power of attorney statutes (18 states plus the District of Columbia have durable power of attorney laws which permit designated agents to make medical decisions, including life-support treatment decisions) address not so much the content of medical decisions, but rather who is authorized to make them. The same can be said for surrogate decision making provisions in state laws (13 states have such provisions) that outline those persons authorized to make medical decisions on behalf of an incompetent person who has not executed a prior directive. Nearly every state has at least one of these protections.

Much has been written during the past 15 years about the promises and perils of living will laws: the welcome support in law for honoring patients' wishes, expanding advocacy for such legislation by health care professionals, the provision of civil and criminal immunity from liability to the health care provider who honors such a document, the ambiguity of terms such as "terminal condition" and "life-sustaining treatment," not to mention the stubborn debate over artificial nutrition and hydration.

Yet it is sometimes difficult to know what kind of conversation will be most useful for future medical decision making. Underlying all exhortations to execute advance directives is the belief that future medical conditions and available treatments can be anticipated, and that a person can reasonably predict how he or she will make judgments in such situations. But these assumptions are problematic. It is difficult, if not impossible, to predict with

any accuracy (1) what medical condition one might find oneself in; or (2) the range and nature of specific treatment options that might be available, in the future, to one's surrogate decision makers. Traditional living wills are based on an implied assumption that there are inherent moral attributes of certain conditions (e.g., terminal illness) and treatments (e.g., artificial hydration and nutrition) that are self-evident and "speak for themselves." This assumption also warrants further scrutiny. As people are asked to consider future treatment options, especially if they understand something more than, "I would never want to be hooked up to machines the way my uncle was," they find themselves saying, "Well, it depends."

In their quest for documented medical conclusions, traditional advance directives have overlooked the premises upon which even present health care decisions are based. For example, it is difficult to predict whether one would definitely opt for a ventilator, hydration and nutrition, or antibiotics without actually being in the situation itself. It is possible, however, to articulate the values that matter now to the individual for whom such a decision might later be made. In asking for guidance concerning future treatment decisions, we typically ignore the primacy of values, wishes, preferences, and beliefs that underwrite medical decision making.

In seeking guidance for future treatment decisions, we must pay attention to the values, ideals and beliefs that underwrite medical decision making.

Two recent innovations in advance directives move these traditional forms in opposite directions. The Medical Directive probes more deeply into a concrete medical condition/treatment matrix, by posing specific circumstances or situations, listing 12 possible medical interventions, and asking the person to check one of the following for each treatment: "I want," "I do not want," "I am undecided," or "I want a

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trial: if no clear improvement, stop treatment."

The Values History, by contrast, makes little mention of condition or treatment. Instead, it targets those values, preferences, and beliefs that serve as premises for present and future medical decision making. Our medical choices issue in large part from our attitudes toward independence and control and toward our overall health status, our perception of the role of our physician and other health care providers, our philosophical perspectives on life, illness, dying and death, our religious background and beliefs, our living environment, and our concerns about finances.

Discussion of these foundational values can provide important information for friends, family members, physicians and others who might, in the future, have to make medical decisions for us when we are no longer able to do so. By talking about these issues ahead of time, family disagreements may be minimized. And when such judgments do need to be made, the burden of responsibility may be lessened because others feel confident of one's wishes.

Who should consider preparing a Values History form? Everyone. While it has been customary to focus on older people, it is just as important that younger people discuss these issues and make their wishes known. Often some of the most complex problems arise in caring for younger patients. If they had talked with families and friends, these surrogate decision makers could feel reassured they were following the patient's wishes.

The Values History is the product and ongoing focus of the National Values History Project, now in its third year of revising and disseminating the form. The project grew out of the 1987-88 Medical Treatment Guardian Program, in which volunteers throughout New Mexico were trained to serve as temporary medical treatment guardians for hospitalized patients who had no family or identified decision maker.

These volunteers devised a "Values Inventory," a list of questions that were often asked of others about the patient. Because it was unlikely that these patients had articulated clear medical decision making instructions in advance, questions contained in the inventory did not focus on conditions or treatments. It was recognized that each patient carried a unique value system comprising personal wishes, pref-

erences, and beliefs which would either be served or disserved by subsequent decisions.

Our medical choices flow from our attitudes toward independence and control and toward our overall health status, our perception of the physician's role, our philosophical posture facing life, illness, dying and death, our religious convictions, our living environment, and our concerns about finances.

The form's name was later changed to "Values History," thereby reflecting our lived experience that one's ideals, convictions, and desires evolve continuously through life. Appropriately, individuals and institutions have revised and adapted the form for their own use. And yet, despite such "personalizing," certain initial assumptions and observations remain constant:

- (1) The form is not intended to substitute for any formal or legal advance directive.
- (2) Underlying most medical choices are those values and beliefs that matter most to an individual.
- (3) Health care professionals, as a group, generally have not executed advance directives themselves.
- (4) When making life-support treatment choices, uncertainties may arise because earlier and ongoing "ordinary" decisions have not been approached in the context of a person's value system.
- (5) Learning to identify and express one's deepest values is the work of a lifetime, to be started early and understood as a continuing "work in progress."
- (6) People are more concerned with how to "live well until I die" than with dying *per se*. It is important to reflect not so much on "How I want to die," but rather on "How I want to live until I die."
- (7) The intensive care unit, or the occasion of a medical crisis, is the worst place, or time, to begin such work.

The Medical Directive has the

advantage of situational specificity. It fails, however, to inquire, "Why?" It may encourage early (premature?) decision making, without attending to the attitudes and deliberations pivotal for life-and-death judgments. A surrogate, faced with a situation not anticipated in the Directive's hypothetical scenarios, may still not know how the patient him- or herself would approach such a decision. Medical conditions and proposed treatments are, by themselves, silent without knowing what they might mean for the patient.

Perhaps more than any other document, the Values History is able to balance the inescapable tensions that characterize the lives of persons who live through time. The shift in the form's name, from Values Inventory to Values History, captures our need to take a momentary photograph of a person who will never again exist in just that manner, as well as our sensitivity to the ever-changing process of developing personhood. Values are the lived sources of meaning for a person, and they actively constitute a person's history as they are put into words.

What we are learning is that as a society we have developed neither the language nor the habit for noting and expressing such beliefs and values as they evolve and mature over time. When we find ourselves with no alternative but to attempt this discussion, usually at a time of personal or family crisis, we find ourselves exquisitely inarticulate. Yet it is precisely such conversation, both because of its substance as well as the fact of its occurrence, that can spare families, friends, and physicians the burden of making treatment decisions in the face of ignorance and uncertainty about the patient's wishes.

References

1. Linda L. Emanuel and Ezekiel J. Emanuel, "The Medical Directive: A New Comprehensive Advance Care Document." *Journal of the American Medical Association* 261 (1989), pp. 3288-3293.
2. Joan McIver Gibson, "Reflecting on Values." *Ohio State Law Journal* 51 (1990), pp. 451-471.
3. Pam Lambert, Joan McIver Gibson, and Paul Nathanson, "The Values History: An Innovation in Surrogate Decision-Making." *Law, Medicine & Health Care* 18 (1990), pp. 202-212.

VALUES HISTORY FORM

NAME: _____
DATE: _____

Comments: (e.g., whom have you named to be your decision maker?)

If someone assisted you in completing this form, please fill in his or her name, address, and relationship to you.

Name: _____
Address: _____
Relationship: _____

Durable Power of Attorney for Health Care Decisions

Date written: _____
Document location: _____
Comments: (e.g., whom have you named to be your decision maker?)

The purpose of this form is to assist you in thinking about and writing down what is important to you about your health. If you should at some time become unable to make health care decisions for yourself, your thoughts as expressed on this form may help others make a decision for you in accordance with what you would have chosen.

The first section of this form asks whether you have already expressed your wishes concerning medical treatment through either written or oral communications and if not, whether you would like to do so now. The second section provides an opportunity for you to discuss your values, wishes, and preferences in a number of different areas, such as your personal relationships, your overall attitude toward life, and your thoughts about illness.

SECTION 1

A. WRITTEN LEGAL DOCUMENTS

Have you written any of the following legal documents? If so, please complete the requested information.

Living Will

Date written: _____
Document location: _____
Comments: (e.g., any limitations, special requests, etc.) _____

Durable Power of Attorney

Date written: _____
Document location: _____

Organ Donations

Date written: _____
Document location: _____
Comments: (e.g., any limitations on which organs you would like to donate?) _____

B. WISHES CONCERNING SPECIFIC MEDICAL PROCEDURES

If you have ever expressed your wishes, either written or orally, concerning any of the following medical procedures, please complete the requested information. If you have not previously indicated your wishes on these procedures and would like to do so now, please complete this information.

Organ Donation

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____
Comments: _____

Kidney Dialysis

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____
Comments: _____

Cardiopulmonary Resuscitation (CPR)

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____
Comments: _____

Respirators

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____
Comments: _____

Artificial Nutrition

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____
Comments: _____

Artificial Hydration

To whom expressed: _____
If oral, when? _____
If written, when? _____
Document location: _____

Comments: _____

food preparation, sleeping, personal hygiene, etc.? _____

C. YOUR THOUGHTS ABOUT INDEPENDENCE AND CONTROL

1. How important is independence and self-sufficiency in your life? _____

2. If you were to experience decreased physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency? _____

3. Do you wish to make any general comments about the value of independence and control in your life? _____

C. GENERAL COMMENTS

Do you wish to make any general comments about the information you provided in this section?

5. Do you wish to make any general comments about your overall health?

B. YOUR PERCEPTION OF THE ROLE OF YOUR DOCTOR AND OTHER HEALTH CAREGIVERS

1. Do you like your doctors? _____

2. Do you trust your doctors? _____

3. Do you think your doctors should make the final decision concerning any treatment you might need? _____

4. How do you relate to your caregivers, including nurses, therapists, chaplains, social workers, etc.? _____

5. Do you wish to make any general comments about your doctor and other health caregivers? _____

SECTION 2

A. YOUR OVERALL ATTITUDE TOWARD YOUR HEALTH

1. How would you describe your current health status? If you currently have any medical problems, how would you describe them? _____

2. If you have current medical problems, in what ways, if any, do they affect your ability to function? _____

3. How do you feel about your current health status? _____

4. How well are you able to meet the basic necessities of life—eating,

D. YOUR PERSONAL RELATIONSHIPS

1. Do you expect that your family and friends will support your decisions regarding medical treatment you may need now or in the future? _____

2. Have you made any arrangements for your family or friends to make medical treatment decisions on your behalf? If so, who has agreed to make decisions for you and in what circumstances? _____

3. What, if any, unfinished business from the past are you concerned about (e.g., personal and family relationships, professional and legal matters)? _____

4. What role do your friends and family play in your life? _____

5. Do you wish to make any general comments about the personal relationships in your life? _____

7. What goals do you have for the future? _____

8. Do you wish to make any general comments about your attitude toward life? _____

5. How do you feel about the use of life-sustaining measures in the face of: terminal illness? _____

_____ permanent coma? _____

_____ irreversible chronic illness (e.g., Alzheimer's disease)? _____

_____ 6. Do you wish to make any general comments about your attitude toward illness, dying, and death? _____

E. YOUR OVERALL ATTITUDE TOWARD LIFE

1. What activities do you enjoy (e.g., hobbies, reading, sports, etc.) ?

2. Are you happy to be alive ? _____

3. Do you feel that life is worth living? _____

4. How satisfied are you with what you have achieved in your life? _____

5. What makes you laugh/cry? _____

6. What do you fear most? What frightens or upsets you? _____

F. YOUR ATTITUDE TOWARD ILLNESS, DYING, AND DEATH

1. What will be important to you when you are dying (e.g., physical comfort, no pain, family members present, etc.)? _____

2. Where would you prefer to die? _____

3. What is your attitude toward death? What does death mean to you? _____

4. If you were to die tomorrow, are there any important unresolved matters you would want to settle today? If yes, what are they? _____

G. YOUR RELIGIOUS BACKGROUND AND BELIEFS

1. What is your religious background? Do you believe in God or a higher power? _____

2. How do your religious beliefs affect your attitude toward serious or terminal illness? _____

3. Does your attitude toward death find support in your religion? _____

4. How does your faith community, church or synagogue view the role of prayer or religious sacraments in an illness? _____

5. Do you wish to make any general comments about your religious background and beliefs? _____

H. YOUR LIVING ENVIRONMENT

1. What has been your living situation over the last 10 years (e.g., lived alone, lived with others, etc.)?

2. How difficult is it for you to maintain the kind of environment for yourself that you find comfortable? Does any illness or medical problem you have now mean that it will be harder in the future? _____

3. Do you wish to make any general comments about your living environment? _____

I. YOUR ATTITUDE CONCERNING FINANCES

1. How much do you worry about having enough money to provide for your care? _____

2. Would you prefer to spend less money on your care so that more money can be saved for the benefit of your relatives and/or friends? _____

3. Do you wish to make any general comments concerning your finances and the cost of health care? _____

J. YOUR WISHES CONCERNING YOUR FUNERAL

1. What are your wishes concerning your funeral and burial or cremation?

2. Have you made your funeral arrangements? If so, with whom?

3. Do you wish to make any general comments about how you would like your funeral and burial or cremation to be arranged or conducted? _____

OPTIONAL QUESTIONS

1. How would you like your obituary (announcement of your death) to read? _____

2. Write yourself a brief eulogy (a statement about yourself to be read at your funeral). _____

SUGGESTIONS FOR USE

After you have completed this form, you may wish to provide copies to your doctors and other health caregivers, your family, your friends, and your attorney. If you have a Living Will or Durable Power of Attorney for Health Care Decisions, you may wish to attach a copy of this form to those documents.