

# Reflecting on Values

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Illness often is the occasion of remarkably teachable moments, for both patient and caretaker. The National Values History Project<sup>1</sup> (the "Project"), initially nothing more than an effort to supplement advance medical directives, such as living wills and durable powers of attorney, has developed into a qualitatively different way of looking at health care decisions and the persons who make them. The Project provides a way for people to discuss and document their wishes and preferences so that surrogate decisionmaking, if it should become necessary, will reflect an individual's desires. This essay will try to weave together several issues of contemporary health care decisionmaking against a background of more traditional philosophical analyses, in hopes that the resulting tapestry presents itself as both fresh and familiar to those most intimately connected with such decisionmaking.

The Project grew out of the 1987-88 Medical Treatment Guardian Program<sup>2</sup> ("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 decisionmaker. Hospital ethics committees in Albuquerque and Santa Fe had begun to identify such "anonymous" patients as a growing source of serious legal and ethical problems in their institutions. For example, the committees were faced with trying to determine what had happened to any manifestation of community for these patients, most of whom came from long term care facilities or from the ranks of the homeless. The committees were also faced with having to determine who these patients were and what they wanted decided on their behalf.

In response to the difficulties facing the hospital ethics committees, the Guardian Program volunteers tried to reestablish connection with patients, sought ways to enhance the patients' autonomy and dignity, and applied the principle of substituted judgment wherever possible. As patients, particularly the elderly, voiced concern that their wishes often are ignored when medical decisions are made on their behalf, the need for a practical mechanism for documenting an individual's choices and values ahead of time became both clear and urgent. The volunteers thus devised a "Values Inventory"—a form containing a list of interview questions about what most concerned their wards. The questions generally were not medical in nature, since the likelihood that these

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1. The National Values History Project (1989-90) currently being administered by the Center for Health Law and Ethics, Institute of Public Law, The University of New Mexico School of Law, was made possible through a grant from the Ittleson and Retirement Research Foundations.

2. The Medical Treatment Guardian Program, also administered by the Center for Health Law and Ethics, Institute of Public Law, The University of New Mexico School of Law, was funded by the Retirement Research Foundation.

patients would have articulated clear medical decisionmaking instructions in advance was virtually nil. Yet each patient undoubtedly had a values system that included wishes, preferences, and beliefs which would either be served or dis-served by subsequent decisions.

Over time, the form's name was changed to "Values *History*," reflecting evolution, continuity, and the constitutive nature of desires, choices, and convictions for the persons living them. Almost immediately, those administering the Values History form on behalf of others realized the importance and utility of people undertaking the process for themselves, while they still possessed the capacity to do so. The Project therefore shifted the emphasis away from surrogate decisionmakers and toward those still in control of their own decisionmaking.

It was initially thought that those positioned "on the brink," so to speak, might have an increased interest in discussing the issue of medical decision-making on their behalf. The Project therefore targeted residents of long term care facilities, members of retirement communities and congregate living arrangements, hospice patients, and recipients of home care services. Parishes and church groups used the Values History form in adult education classes, and an intergenerational version of the Values History form was developed for high school students to complete themselves and then to take home to discuss with their parents and grandparents.

During the Project, the Values History form has undergone constant revision based on the reported experience of those piloting the process throughout the country. The tendencies to personalize the process and to transform it from a passive (administered) chore into an active, self-generated process and product have been hallmarks of the Project. For example, following the Guardian Program volunteers' recommendation that the Values History form be used by primary decisionmakers, those piloting the use of the form with friends, colleagues, and patients have discovered the importance of undertaking the process *themselves*.

Those piloting the use of the form understand that the Values History form is in no way intended to substitute for any formal or legal advance directive, such as a living will or durable power of attorney. They have remarked, however, that whereas such formal directives ask for a series of medical *conclusions*, the Values History form targets value premises that are not medical in nature but are always considered (consciously or not) when making medical decisions. Other advance directives require one to anticipate medical conditions that might arise and to decide in advance what medical treatment one would choose or not choose. No mention is made about who the individual is now, what matters to the individual, or why the individual has made the choices he has—in short, no attention is paid to the only information that is real and not hypothetical. These insights gathered over the past several years may account for the unexpected appeal of the Values History form, especially to persons whose job requires them to encourage others to execute advance directives, such as health care professionals, administrators, pastors, and counselors.

The Values History form has also weakened the inverse relationship between health care professional status and the execution of advance directives.<sup>3</sup> It has been observed that, while these professionals often lament that those they care about have not made adequate plans for their surrogate decisionmakers, the professionals' own performance in this area is dismal. Recently, however, an increasing number of health care professionals are reporting that they have begun to use the Values History form for themselves and for their family. Those administering the Project are therefore interested in determining why health care professionals and others seem to prefer the Values History form over traditional, medically-oriented advance directives. Perhaps an answer lies in the explicit attention paid to the language of values and to linguistic and aesthetic analyses that have, until recently, remained outside medical discourse.

A starting point for such a linguistic and aesthetic analyses might be our human capacity for self-referential thought and language, and the use of both discursive (representational) and non-discursive (presentational) symbols to communicate meaning. Such analyses can be found in the literature of linguistic philosophy and aesthetics, but it is a relative newcomer to the field of health care decisionmaking. We currently spend our time talking, writing, and reflecting about what should be done medically and about how such decisions should be made. Physicians study the anatomy of a medical decision; ethics committees deliberate about complex health care issues; national councils and task forces develop guidelines for making certain kinds of medical decisions with social policy implications; lawyers and courts review the propriety of medical behavior and decisionmaking; and some of us prepare and deliver verbal or written directives to prospective surrogate decisionmakers who may assume authority and responsibility for our decisions when we no longer possess such capacity. Such discourse is both prospective and retrospective in nature, and it appears that no situation or decision is immune from such scrutiny, analyses, and verbiage. One can imagine Antonio Salieri protesting, "Too many words!"

Medical science and art generally make use of language in its discursive and descriptive capacity. Medical terms are to be understood literally as discursive symbols; they *represent* something else and are important and useful only in so far as they point to something other than themselves, such as conditions, diseases, treatments, or organ systems. Medical terms are individually definable, one-dimensional units which, in combination, still return to the basic units for an analyses of meaning. For example, one might overhear a physician remark, "although the severely burned patient has less than a 2% chance of survival, we still got a good brain out of our last intervention." This is also the language of legal documents, such as living wills and durable powers of attorney.

Thought and language also have the non-discursive power to *reflect* and *present*. Jacob Bronowski and others have observed that language's power of self-reference, that is, to "talk about itself," accounts not only for reflexivity, but for the ability to present or express its own form with exceptional clarity

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3. See, e.g., Gibson, *Values History Focuses on Life and Death Decisions*, 5 MED. ETHICS FOR PHYSICIAN 1 (Feb. 1990).

and immediacy.<sup>4</sup> The paradox of the Lying Cretan (the Cretan who declares that "All Cretans lie") and the wall-hanging that asserts, "The statement in this frame is false," have been used to demonstrate this curious potential of language for the coincident presentation of opposing and reflexive frames of reference. Language's *expressive* and *presentational* powers can be seen when language itself is viewed as art.

It is no coincidence that storytelling in medical settings is gaining respectability, and it may explain why a seemingly objective and discursive document such as the Values History form has turned into something quite radical (in the root sense of that word): a medium not so much for the representation of disembodied wishes, preferences, and beliefs possessed by persons generally, but rather for the ongoing presentation of a unique subject—a person. Perhaps more than any other form thus far, the Values History form is able to accommodate the inevitable tension between the need to take a photograph of a moment (a person) which, once snapped, never again will exist in just that manner—and the importance of understanding the ongoing, 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 to words.<sup>5</sup>

The interest in bioethics over the past several years signals a need to reflect on and express the meaning of the choices we as a society have made and must make. The Values History form seems to have come along at a time when individuals want to personalize and direct such reflection. Developing and expressing one's own values history requires attending to what is personal and unique. As E.F. Schumacher says, paying attention and directing attention are the hallmarks of self-awareness.<sup>6</sup>

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4. See, e.g., Bronowski, *The Logic of the Mind*, 35 AM. SCHOLAR 236-37 (1966).

5. See *infra* Appendix A for a reproduction of the Values History form and *infra* Appendix B for a reproduction of the Intergenerational version of the Values History form.

6. E.F. SCHUMACHER, A GUIDE FOR THE PERPLEXED 66 (1977).

## Appendix A

## VALUES HISTORY FORM\*

Name: \_\_\_\_\_ Date: \_\_\_\_\_

If someone assisted you in completing this form, please fill in their name, address, and relationship to you:

\_\_\_\_\_  
 \_\_\_\_\_

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 of this form 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 I

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: \_\_\_\_\_

Comments: \_\_\_\_\_

(e.g., who have you named to be your decision maker?)

## Durable Power of Attorney for Health Care Decisions

Date written: \_\_\_\_\_ Document location: \_\_\_\_\_

Comments: \_\_\_\_\_

(e.g., who have you named to be your decision maker?)

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Organ Donation

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: \_\_\_\_\_

C. General Comments

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

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

SECTION II

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?

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\_\_\_\_\_  
\_\_\_\_\_

4. How well are you able to meet the basic necessities of life — eating, food preparation, sleep, personal hygiene, etc.?

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

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B. Your perception of the role of your doctor and other health caregivers

1. Do you like your doctors?

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2. Do you trust your doctors?

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

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

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

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C. Your thoughts about independence and control

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

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

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

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D. Your personal relationships

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

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- 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?

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

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

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

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E. Your overall attitude toward life

1. What activities do you enjoy (e.g., hobbies, watching T.V., etc.)?

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2. Are you happy to be alive?

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

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

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5. What makes you laugh/cry?

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

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7. What goals do you have for the future?

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

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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.)?

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2. Where would you prefer to die?

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3. What is your attitude toward death?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. 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)? \_\_\_\_\_

\_\_\_\_\_

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

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

G. Your religious background and beliefs

1. What is your religious background?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

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

\_\_\_\_\_

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

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

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

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H. Your living environment

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

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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?

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

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I. Your attitude concerning finances

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

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\_\_\_\_\_  
\_\_\_\_\_

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?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_



## Appendix B

## MEDICAL ETHICS: Intergenerational Discussion Questions\*

Name: \_\_\_\_\_ Date: \_\_\_\_\_

This form is designed to help you in thinking about and writing down what is important to you about your health. If at some time you become unable to make health care decisions for yourself, your thoughts may help others make a decision for you.

Try filling out this form for yourself. Then try discussing it with other people you are close to, such as your family and your friends. You might want to take extra copies of this form home with you and ask your parents if they would like to fill it out. Maybe you could interview your parents by asking them these questions and writing out their answers. We call these "intergenerational" questions because they are good to discuss between the generations—between yourself and your parents, your grandparents, your aunts and uncles.

## SECTION I: YOUR THOUGHTS ABOUT SPECIFIC MEDICAL QUESTIONS

1. Do you think it is a good idea to sign a legal document that says what medical treatments you do and do not want when you are dying? (*This is called a "living will."*) Yes\_\_\_ No\_\_\_
2. Do you think it is a good idea to sign a legal document that allows someone else to make health care decisions for you if you are unable to make these decisions yourself (e.g., if you are in a coma)? (*This is called a "durable power of attorney for health care decisions."*) Yes\_\_\_ No\_\_\_
3. Do you want to donate parts of your body to someone else at the time of your death? (*This is called "organ donation."*) Yes\_\_\_ No\_\_\_
4. Do you think you would want to have any of the following medical treatments performed on you?
  - a. kidney dialysis (*used if your kidneys stop working*) Yes\_\_\_ No\_\_\_
  - b. cardiopulmonary resuscitation, also called CPR (*used if your heart stops beating*) Yes\_\_\_ No\_\_\_
  - c. respirator (*used if you are unable to breathe on your own*) Yes\_\_\_ No\_\_\_
  - d. artificial nutrition (*used if you are unable to eat food*) Yes\_\_\_ No\_\_\_
  - e. artificial hydration (*used if you are unable to drink fluids*) Yes\_\_\_ No\_\_\_

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5. Use this space if you want to explain any of your answers.

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## SECTION II: QUESTIONS ABOUT YOUR LIFE

### A. Your health

1. How do you feel about your current health?

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2. If you have any medical problems, do they affect your ability to function? If yes, how?

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### B. Your doctors

1. If you have a doctor, do you like him or her? Why?

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2. Do you think your doctor should make the final decision about any medical treatments you might need?

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C. Your independence

- 1. Do you consider yourself an independent person? Yes\_\_\_ No\_\_\_
- 2. Do you like to make your own decisions? Yes\_\_\_ No\_\_\_
- 3. If you could not make your own decisions, would you be willing to let others make decisions for you? Yes\_\_\_ No\_\_\_
- 4. Use this space if you want to explain any of your answers.

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D. Your personal relationships

- 1. Do you expect that your family and friends will support your decisions about any medical treatment you might need?

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- 2. Have you made any arrangements for your family or friends to make medical decisions for you? If yes, who has agreed to make these decisions for you and in what circumstances?

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- 3. If a member of your family were unable to make medical decisions, who should make the decisions for that person?

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- 4. Would you want to make medical decisions for members of your family or for your friends? If yes, in what circumstances?

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5. How do you feel about your relationships with your family?

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6. How do you feel about your relationships with your friends?

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E. Your attitude toward life

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

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2. Are you happy to be alive?

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

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

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5. What makes you laugh? What makes you cry?

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

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7. What goals do you have for the future?

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F. Your attitude toward illness, dying, and death

1. Has anyone close to you died? Yes\_\_\_ No\_\_\_

2. What does death mean to you?

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3. What would you fear the most about a terminal illness (*an illness where death is certain*)?

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

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5. Do you think you would like to plan your own funeral, or make decisions about your burial? Yes\_\_\_ No\_\_\_

G. Your religious beliefs

1. What are your beliefs about God or a higher power?

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\_\_\_\_\_  
\_\_\_\_\_

2. Are you an active member of a church? Yes\_\_\_ No\_\_\_

3. Are prayer and worship important to you? Yes\_\_\_ No\_\_\_

4. How is death viewed in your religion?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Suggestions for Use

Share your answers with people who are close to you. You might want to give a copy of this form to your family members, your doctor, your minister, and anyone else with whom you would like to share these thoughts. If you have legal documents concerned with health care (e.g., living will, durable power of attorney for health care decisions), you may wish to attach a copy of this form to your documents.

\* \* \* \* \*

This form is part of a National Values History Project conducted at the Center for Health Law and Ethics, University of New Mexico, through a grant from the Ittleson Foundation. If you would like more information about this project, or if you have suggestions for improving this form, please contact:

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