



Caring Conversations[®]



Making Your Wishes Known for End-of-Life Care

It may be difficult to imagine being too ill to make your own healthcare decisions. Unfortunately, that time may come. Something happens – a critical injury, a debilitating illness, lack of response to a lifesaving treatment – and acting on your own behalf is no longer possible.

Follow the step-by-step approach in this special workbook to make your wishes known for your end-of-life care and to help others do the same.

NAME: _____

DATE: _____

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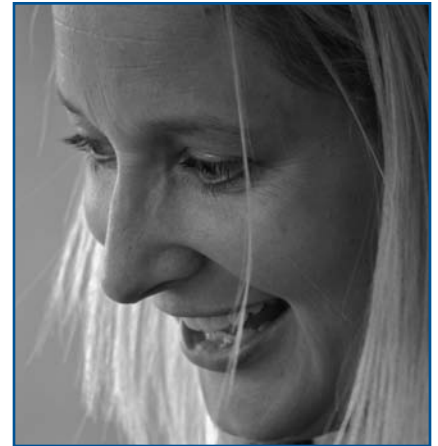
 CENTER FOR PRACTICAL
BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION



They believe that talking about end-of-life wishes is a gift that we should give each other.



We all need comfort and peace of mind when a family member is seriously ill.



The Center for Practical Bioethics, located in Kansas City, Missouri, is a nonprofit, freestanding organization nationally recognized for its work in practical bioethics. Since its inception in 1984, the Center has helped patients and their families, healthcare professionals, policymakers, and corporate leaders grapple with ethically complex issues in medicine and research.

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Information about *Caring Conversations*®

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Caring Conversations® workbooks are available for individual purchase, in bulk quantities for institutional use, or as part of a *Caring Conversations*® program. For more information about the *Caring Conversations*® program, call the Center at 816 221-1100; fax your request to 816 221-2002; or visit our website at www.PracticalBioethics.org.

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Reflect, Talk, Appoint, Act

Introduction

Sharing your healthcare preferences with family and friends is one of the most important conversations you will ever have. No matter what your age or health condition, it is important to think about how you want to be cared for during the last months/days of your life.

Caring Conversations®, developed by the Center for Practical Bioethics, is designed to guide you and your family and friends through this process. It gives you a framework for considering what is most important to you and guidance on communicating your wishes to loved ones, healthcare providers and, especially, the person you choose to speak for you. *Caring Conversations*® also equips you with information you need to formalize your wishes for end-of-life care (Durable Power of Attorney for Healthcare Decisions and Healthcare Treatment Directive).

You will find that *Caring Conversations*® is an EMPOWERING experience. You gain peace of mind, knowing your wishes will be honored. Your loved ones gain greater understanding and a sense of confidence, knowing how to act in your best interest when that time comes.

When you complete this workbook and the two documents that make up your advance directive, list below the individuals/institutions who have received copies (include names and contact information).

Your completed *Caring Conversations*® workbook

Durable Power of Attorney for Healthcare Decisions

Healthcare Treatment Directive

Reflect, Talk, Appoint, Act

Step One:

Reflect upon what is most important to you

You may wish to complete this questionnaire alone or you may choose to do it with someone. There are no 'right' or 'wrong' answers to the questions. Each set of questions is intended to help you come to terms with your preferences for end-of-life care. Your written responses will help others better understand your wishes.

Acknowledging your beliefs, values and concerns

Imagine that you are in the last six months of your life. For many, the end of life is a call to complete unfinished business – a time to reexamine the relationships, events, values, decisions and tasks of greatest importance.



She shared stories with her grandson about a quilt her mother had made.

What life events have given you the most joy and fond memories?

What life events have saddened you the most or caused you regret?

What is important for others to know about the spiritual or religious part of your life?

What concerns do you have about your health or future healthcare? _____

What concerns do you have about making decisions for yourself late in your life? _____

What do you most value about your physical or mental well-being? For example, do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? _____

Are there circumstances under which you would refuse or discontinue treatment? If so, describe those circumstances and timeframes.

Are there special ways you want to share time with friends and family? Would you want to have a private visit with some of the special people in your life? Do you have special memories you would like to share? With whom would you share them?

Coming to terms with dying

In his book, *Dying Well*, Dr. Ira Byock suggests five phrases that dying people want to share:

- "I forgive you,"
- "please forgive me,"
- "I love you,"
- "thank you," and
- "good-bye."



He knew he had time to write a book about living after his terminal diagnosis.



They knew the race to cure cancer would be long.

Think about the above phrases as you consider the following questions.

Are there people to whom you may want to write a letter or record a message (perhaps marked for opening at a future event)? Do you know what you would say?

Would you want to travel to a special place or take a trip to visit family and friends? If so, where would you go? What would you do?

Do you want a special gathering, such as a reunion with family and friends, a prayer service or an event to share memories, old stories and songs?

What spiritual, religious and psychosocial support do you want as you near death? Do you want to pray with a member of the clergy, be read to from spiritual or religious texts, or listen to poetry or tapes? Is there special music you would like to hear? _____

What are your thoughts about your funeral or memorial service? Do you have any favorite songs or readings? Are there special people you hope will participate? _____

Making end-of-life decisions

If your physician believes there is no reasonable hope that you will recover and you can no longer make decisions for yourself:

How important is good pain management? (For example, would you want to be sedated if it were necessary to control your pain?)

Would you want palliative care (treatment of your symptoms to make you more comfortable) to manage conditions like nausea, breathing, anxiety, fatigue and sleep?

If you could no longer swallow, would you want to be tube fed? For how long? _____

Consider the following circumstances as you ponder this question:

- (1) Permanently unconscious or a persistent vegetative state;
- (2) Unable to communicate with family and friends;
- (3) No reasonable expectation of recovery.

If the opportunity to participate in a research study were available, would you want your agent to consider your participation? _____

Where do you want to be when you are in the last stages of dying? (Would you prefer to be at home, if possible, in a hospital or some other place?) _____



She always loved music and singing even when the words would not come.

What do you think would make you comfortable? Do you want privacy and quiet or would you prefer to have the company of loved ones and friends? _____

Do you wish to donate your organs and tissue? _____

Do you want to donate your body for medical science? If yes, to what institution? _____

Would you agree to an autopsy? _____

Do you prefer burial or cremation? _____



Step Two:

Talk to loved ones about your treatment preferences

Appoint a surrogate decision maker.

Ask yourself this question: If I were seriously injured in an accident today, who would be gathered at the hospital?

The individuals who you list are likely to be the group with whom you may wish to have your caring conversation. List them here. _____



She was very clear when she expressed her wishes.

Hold a caring conversation with loved ones

Many of the predictable milestones of life are observed with social rituals – birthdays, graduations, weddings, retirements, and deaths. However, social rituals that mark life’s last chapter are uncommon. Patients die in pain that could and should be managed. Seriously ill patients and their families needlessly suffer spiritual, psychological, and social distress. Too often, the financial costs of care for dying patients are catastrophic, but the benefits of the care are marginal. Preferences concerning care are not expressed or heard, or they are heard but not respected.

Caring Conversations® provides a social ritual to help you and your loved ones plan the kind of healthcare you will want at the end of life. Sharing the information in your *Caring Conversations*® workbook allows others to understand and respect your wishes and moderates the tension that patients and their families often experience during a last illness.

End-of-life care is not a subject that most people are comfortable discussing. It is helpful to talk about specific kinds of events that frequently raise issues about treatment preferences.

Consider the following situations and discuss your preferences when:

- 1) Treatment for an advanced stage of cancer fails;
- 2) You don't respond for more than a month following a stroke;
- 3) You suffer a severe head injury in a car accident;
- 4) You are in an advanced stage of Alzheimers.

The more you express your choices regarding end-of-life care, the more confidence and peace of mind you and your loved ones will have in making these decisions.



She has confidence in her physician and in her own healthcare decisions.

Appoint a surrogate decision maker

Who do you want to make your healthcare decisions when you cannot make them for yourself? Who would be your second choice? (Consider those in the group you named on page 7.)

This individual will serve as your 'agent' or durable power of attorney (DPOA) for healthcare. Ideally, he or she will be a family member or close friend – someone who knows and understands your values and will act on your wishes confidently and decisively.

When you have named your representative and an alternate, talk with them about your wishes. Then tell your family and close friends whom you have named and why and encourage them to support this individual in following your wishes. [Step Three outlines how to formalize this relationship.]

Step Three:

Act – Prepare an advance directive

'Advance directive' is a general term used to describe a **Durable Power of Attorney for Healthcare Decisions** and a **Healthcare Treatment Directive**. It is also used to refer to living wills and informal directives people may set down in letters or conversations.

An advance directive allows you to communicate your healthcare preferences when you can no longer make your own decisions. The U.S. Supreme Court has recognized that adults with decision-making capacity have a constitutional right to refuse any medical treatment, including ventilators and feeding tubes, and to name an agent to act on their behalf. State laws also support advance care planning.

A **Durable Power of Attorney for Healthcare Decisions** is a legal document that allows you to name a person to make healthcare decisions for you. It is valid in any state so long as it is signed and witnessed in accordance with State law.

In most cases, the durable power of attorney becomes effective only when you are no longer able to make decisions for yourself. In some cases, you may want your agent to help you make decisions even though you are still capable of making some decisions for yourself. When you fill out

the form in this workbook, you will be able to choose between these options. You may make your power of attorney effective on the date you sign the document or it will become effective when you no longer have the capacity to make and communicate your healthcare decisions.

A **Healthcare Treatment Directive** is a legal document that allows you to state in advance your wishes regarding the kind of healthcare treatment you want when you cannot make or communicate these decisions.

Your agent will be guided by the treatment directive when acting on your behalf. If you do not appoint an agent, it is important to complete the healthcare directive and give copies to your medical providers and others to help them know your preferences when you can no longer speak for yourself.

A sample of each form, along with frequently asked questions, can be found at the end of this workbook.

Step Four:

Periodically review the contents of your *Caring Conversations*[®] workbook and other key documents

Your preferences for end-of-life care may change over time. From time to time, read over the entries in your workbook, review your advance directive (dating and initialing any changes that are made), and continue having conversations with family, friends and healthcare providers about your wishes for end-of-life care. *Caring Conversations*[®] is an ongoing process.

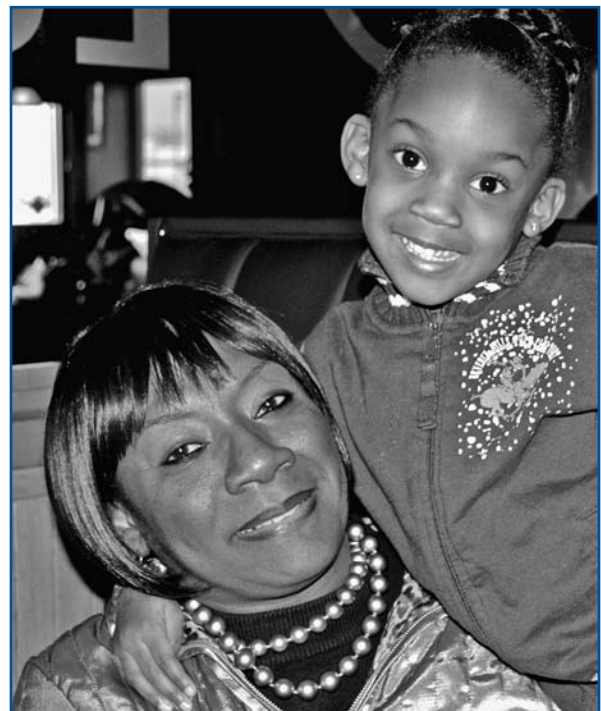
This may also be a good time to (1) review any financial arrangements that you want others to be aware of (e.g., long-term care insurance, transfers of property, providing for dependents, designating charitable contributions); and (2) confirm where you keep information about your

bank account, insurance policies, stock certificates, deeds and titles, and who has access to this information.

Step Five:

Encourage family members and others in your community to participate in *Caring Conversations*[®]

Some day you may have to make decisions for someone you love – maybe a parent or your spouse. You may have tried to have a conversation and been told that they don't want to talk about it. Sharing your *Caring Conversations*[®] workbook may help. If it doesn't, ask for their help. Tell them that you love them and, if you ever have to make decisions for them, you want to know you are doing what they want. You might say, "Dad, I need you to do this for ME. I need your help now while we can have this conversation – long before we need it."



She knew she could lean on her grandmother.

Setting the example is a great motivator for others to follow your lead. Share your *Caring Conversations*® workbook and encourage others to take advantage of this tool to make their wishes for end-of-life care known.



A child's love does not end.



Reaching out makes caring conversations easier.

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■ Frequently Asked Questions about Advance Directives

1. Do I need both a Durable Power of Attorney for Healthcare Decisions and a Healthcare Treatment Directive?

No. At a minimum you should consider appointing a Durable Power of Attorney for Healthcare. A Treatment Directive is used to inform your agent about your wishes or guide your medical providers should an agent not be available. Discuss your *Caring Conversations*® workbook and your Healthcare Treatment Directive with your agent.

2. How does a Healthcare Treatment Directive differ from a living will?

The Healthcare Treatment Directive is similar to a living will because it is a signed, dated, and witnessed document that allows you to state in advance your wishes regarding treatment when you are seriously ill or at the end of life. The difference is that most living wills affect only conditions when you are terminally ill. The Healthcare Treatment Directive becomes effective whenever you lose your ability to make and communicate decisions.

3. How is the Durable Power of Attorney for Healthcare Decisions different from other powers of attorney?

A Durable Power of Attorney for Healthcare Decisions allows you to name a person (agent) to make healthcare decisions for you. It takes effect only when conditions warrant; you lose the ability to make or communicate decisions. Usually people name separate agents for powers of attorney for financial matters and durable powers for healthcare decisions and must use separate

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■ Preparing an Advance Directive

The advance directive included in the *Caring Conversations*® workbook is designed to help you document your wishes about healthcare. It has two parts (complete one or both of these forms):

Durable Power of Attorney for Healthcare Decisions – a document that allows you to name a person to make healthcare decisions for you.

Healthcare Treatment Directive – a document that allows you to state in advance your wishes regarding the kind of healthcare treatment you want when you cannot make or communicate these decisions.

Refer to the frequently-asked-questions section for more detailed information.

Completing the *Caring Conversations*® workbook first will make the process of preparing an advance directive easier.

documents to do so. If you combine your durable powers of attorney in a single appointment you clearly state both powers. The document in this book addresses healthcare matters only.

4. Whom should I name as my agent?

Name a person as your agent who knows your goals and values and whom you trust to carry out your wishes. You may name a family member, spouse, an adult child, a close friend or other loved one. Talk with your agent about your wishes in detail and confirm that he or she agrees to act on your behalf. Share your *Caring Conversations*® workbook with your agent and others such as family, physicians, clergy, attorney.

5. If I have already completed a living will or other advance directive, do I need a Healthcare Treatment Directive or Durable Power of Attorney for Healthcare Decisions?

Living wills are usually not as comprehensive as the Healthcare Treatment Directives and don't allow you to name an agent. Review any previously completed documents and discuss any needed changes with your healthcare providers before completing either document.

6. Do I need an attorney to make a Healthcare Treatment Directive or a Durable Power of Attorney for Healthcare Decisions?

No. However, you may want to discuss your advance directive with your attorney, if you have one.

7. Do advance directives need to be witnessed or notarized?

Yes. Witnessing and notarizing requirements vary by state and from document to document. States typically require adult witnesses. Limits on who may witness are also common. Because states differ, it is a good idea to have advance directives both witnessed and notarized.

8. Does the federal privacy rule known as HIPAA affect the ability of the agent I appoint as my durable power of attorney for healthcare to make healthcare decisions for me?

Individual patients are not subject to HIPAA rules. Agents acting as durable powers of attorney for healthcare have the same rights as the patients who appointed them.

HIPAA allows "covered entities," such as hospitals and nursing homes, to use or disclose the information contained in a durable power of attorney for healthcare document to help identify, locate, and notify your agent that he or she is needed.

9. What effect does HIPAA have on my healthcare directive?

When a copy of your healthcare directive is placed in your medical record, it becomes part of the protected health information. However, because HIPAA authorizes covered entities to disclose relevant protected health information to family members, other relatives, or close friends who are involved with a patient's care, HIPAA should not have any effect on your healthcare directive. HIPAA prohibits "covered entities," such as hospitals and nursing homes, from making unauthorized disclosures of "protected health information."

10. What do I do with my completed advance directive?

Make copies of your advance directive to provide to any agent(s) named in your Durable Power of Attorney for Healthcare Decisions and other appropriate individuals (i.e., physicians, family, friends, clergy, and attorney). You may also want to register your advance directive with an online repository so that your agent or healthcare providers can retrieve it electronically.

11. When does my advance directive go into effect?

So long as you can make decisions, it is both your right and your responsibility to make your own decisions. Normally, your advance directive goes into effect only when you lose capacity and can no longer make or communicate your decisions.

12. How long will my advance directive be effective?

Generally, your advance directive is effective until the time of your death. We recommend that you review your advance directive periodically, especially when there is a change in your health status.

13. May I change or revoke my advance directive?

Yes, you may change or revoke it at any time, either verbally or in writing.

14. Will my advance directive be valid in another state?

Yes, especially if it is both notarized and witnessed. The right to make an advance directive has been constitutionally affirmed.

15. Can I expect healthcare providers to carry out the directions in my advance directive?

Yes, in general, healthcare providers have both legal and ethical duties to respect patient directions, whether verbal or written. An agent can help ensure that your wishes are known and honored, advocating on your behalf. If your directive is not being honored, you or your agent can ask for help from an ethics committee, social worker, chaplain, or ombudsman.

16. Will my advance directive be honored in an emergency situation?

It depends on your condition and orders written by your doctor and whether it is available to first responders.

17. Will my advance directive prevent me from getting cardiopulmonary resuscitation (CPR) if my heart stops or I stop breathing?

Not in most cases. A very specific document called a Do Not Resuscitate order (DNR order) must be ordered by your doctor.

If your advance directive addresses the subject of resuscitation, it may be used as evidence of your consent to a DNR order during times of incapacity.

18. Can my advance directive or decisions made by my agent be overridden by my family members?

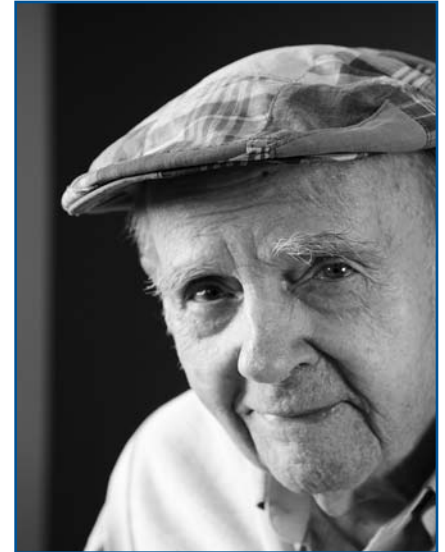
They shouldn't be. Advance directives and decisions made by an appointed agent are morally and legally binding. In practice, however, they are not always honored. The best assurance that they will not be overridden is conversation about these matters with your loved ones and healthcare providers. Instruct your agent to use your healthcare treatment directive as a guideline. He or she may have to make decisions for you in clinical situations that you have not anticipated.

19. Can someone else complete an advance directive for me without my participation?

No, an advance directive is your statement of your preferences.

20. May I state my wishes for things after I die like organ donation in my Advance Directive?

Generally, yes. You may also want to complete an organ donor card and discuss your wishes with your loved ones. In some cases, state law may limit the power of your agent once you have died.



He feels secure that his son will honor his wishes.

We encourage you to complete the *Caring Conversations*® workbook, discuss your healthcare treatment preferences with those who care for you, and indicate that you have done so on your advance directive. The more you express your choices regarding end-of-life care, the more confidence and peace of mind you and your loved ones will have in making these decisions.



Next Step:

Your Durable Power of Attorney for Healthcare Decisions & Healthcare Treatment Directive

Durable Power of Attorney for Healthcare Decisions

■ **Take a copy of this with you whenever you go to the hospital or on a trip** ■

It is important to choose someone to make healthcare decisions for you when you cannot make or communicate decisions for yourself. Tell the person you choose what healthcare treatments you want. The person you choose will be your agent. He or she will have the right to make decisions for your healthcare. If you DO NOT choose someone to make decisions for you, write NONE on the line for the agent's name.

I, _____, SS# _____ (optional), appoint the person named in this document to be my agent to make my healthcare decisions.

This document is a Durable Power of Attorney for Healthcare Decisions. My agent's power shall not end if I become incapacitated or if there is uncertainty that I am dead. This document revokes any prior Durable Power of Attorney for Healthcare Decisions. My agent may not appoint anyone else to make decisions for me. My agent and caregivers are protected from any claims based on following this Durable Power of Attorney for Healthcare. My agent shall not be responsible for any costs associated with my care. I give my agent full power to make all decisions for me about my healthcare, including the power to direct the withholding or withdrawal of life-prolonging treatment, including artificially supplied nutrition and hydration/tube feeding. My agent is authorized to:

- Consent, refuse, or withdraw consent to any care, procedure, treatment, or service to diagnose, treat, or maintain a physical or mental condition, including artificial nutrition and hydration;
- Permit, refuse, or withdraw permission to participate in federally regulated research related to my condition or disorder;
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home, or other healthcare organization; and, employ or discharge healthcare personnel (any person who is authorized or permitted by the laws of the state to provide healthcare services) as he or she shall deem necessary for my physical, mental, or emotional well-being;
- Request, receive, review, and authorize sending any information regarding my physical or mental health, or my personal affairs, including medical and hospital records; and execute any releases that may be required to obtain such information;
- Move me into or out of any State or institution;
- Take legal action, if needed;
- Make decisions about autopsy, tissue and organ donation, and the disposition of my body in conformity with state law; and
- Become my guardian if one is needed.

In exercising this power, I expect my agent to be guided by my directions as we discussed them prior to this appointment and/or to be guided by my Healthcare Directive (see reverse side).

If you DO NOT want the person (agent) you name to be able to do one or other of the above things, draw a line through the statement and put your initials at the end of the line.

Agent's name _____ Phone _____ Email _____
 Address _____

*If you do **not** want to name an alternate, write "none."*

Alternate Agent's name _____ Phone _____ Email _____
 Address _____

Execution and Effective Date of Appointment

My agent's authority is effective immediately for the limited purpose of having full access to my medical records and to confer with my healthcare providers and me about my condition. My agent's authority to make all healthcare and related decisions for me is effective when and only when I cannot make my own healthcare decisions.

SIGN HERE for the Durable Power of Attorney and/or Healthcare Directive forms. Many states require notarization. It is recommended for residents of all states. Please ask two persons to witness your signature who are not related to you or financially connected to your estate.

Signature _____ Date _____
 Witness _____ Date _____ Witness _____ Date _____

Notarization:

On this ____ day of _____, in the year of _____, personally appeared before me the person signing, known by me to be the person who completed this document, and acknowledged it as his/her free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____
 Commission Expires _____

Healthcare Treatment Directive

■ If you only want to name a Durable Power of Attorney for Healthcare Decisions, draw a large X through this page. ■

I, _____, SS# _____ want everyone who cares for me to know what healthcare I want.

(optional)

I always expect to be given care and treatment for pain or discomfort, even if such care may affect how I sleep, eat, or breathe.

I would consent to and want my agent to consider my participation in federally regulated research related to my disorder or condition.

I want my doctor to try treatments/interventions on a time-limited basis when the goal is to restore my health or help me experience life in a way consistent with my values and wishes. I want such treatments/interventions withdrawn when they cannot achieve this goal or become too burdensome to me.

I want my dying to be as natural as possible. Therefore, I direct that no treatment (including food or water by tube) be given just to keep my body functioning when I have

- a condition that will cause me to die soon, or
- a condition so bad (including substantial brain damage or brain disease) that I have no reasonable hope of achieving a quality of life that is acceptable to me.

An acceptable quality of life to me is one that includes the following capacities and values. (Describe here the things that are most important to you when you are making decisions to choose or refuse life-sustaining treatments.)

Examples: • recognize family or friends • make decisions • communicate
 • feed myself • take care of myself • be responsive to my environment

If you do not agree with one or other of the above statements, draw a line through the statement and put your initials at the end of the line.

In facing the end of my life, I expect my agent (if I have one) and my caregivers to honor my wishes, values, and directives.

For further clarification, please refer to my *Caring Conversations*® workbook, which is located at _____

Be sure to sign the reverse side of this page even if you do not wish to appoint a Durable Power of Attorney for Healthcare Decisions

Talk about this form and your ideas about your healthcare with the person you have chosen to make decisions for you, your doctors, family, friends, and clergy. Give each of them a completed copy.

You may cancel or change this form at any time. You should review it often. Each time you review it, put your initials and the date here. _____

Notes:



The Center for Practical Bioethics

Vision:

A society in which the dignity and health of all people are advanced through ethical discourse and action.

Mission:

To raise and respond to ethical issues in health and healthcare.

Core value:

Respect for human dignity.

We believe that all people have intrinsic worth, and we express this belief by promoting both autonomy and social justice in health and healthcare.

We welcome your interest in the *Caring Conversations*[®] program. For more information about *Caring Conversations*[®] or the Center for Practical Bioethics, please contact us at 816 221-1100, visit our website www.PracticalBioethics.org, or email us at bioethic@PracticalBioethics.org.

