



Like natural childbirth, natural dying is a way to cope with one of the great milestones in life, and to help us appreciate that all of life is about connections, relationships, and unconditional love.

— Marilyn Webb, *The Good Death*

workbook

This workbook belongs to

Dated _____

This workbook includes a questionnaire to help you have “caring conversations,” an advance directive document, and a list of the most frequently asked questions about advance directives.

Midwest Bioethics Center
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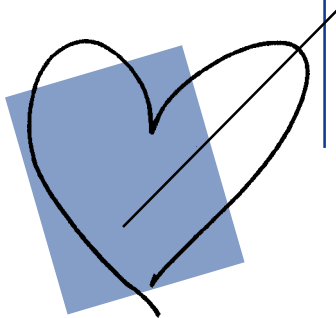
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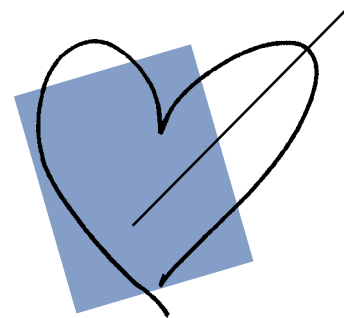
Caring Conversations workbooks are available for individual purchase, for institutional use, or as part of the *Caring Conversations* program. For more information about the *Caring Conversations* program, call Midwest Bioethics Center at (816) 221-1100 or fax your request to (816) 221-2002.

Caring Conversations

Preface

We live within webs of social relationships — family, school, work, faith. We mark many of the predictable landmarks of our lives with social rituals — birthdays, graduations, weddings, retirements, burials. However, social rituals that mark life’s last chapter are uncommon. Without such rituals, the end of life in America is marked in other ways. Patients suffer 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 caring for dying patients are catastrophic, but the benefits of the care are marginal. Preferences concerning care at the end of life are not expressed or heard, or they are heard but not respected. The value of life’s last chapter may be missed entirely.

This *Caring Conversations* workbook provides a social ritual that helps loved ones plan for the end of life. Sharing the information in *Caring Conversations* allows others to understand and respect the preferences of patients who can no longer speak for themselves and eases the tension that patients and their families experience during a last illness. This workbook is intended to help you, your family, and your friends think about these issues now, while you are able to respond to specific questions. Sharing the workbook now will help you and your loved ones find peace of mind in the future. Your preferences may change over time, so revisit your workbook regularly and modify it as necessary. We invite you to use the workbook to prepare yourself and others for your personal ritual of *Caring Conversations*.

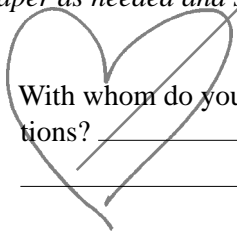


Caring Conversations Questionnaire

For many people, the end of life is a call to complete unfinished business. It offers a time and opportunity to reexamine the relationships, events, values, and tasks that are most important to us — the people and “things” with whom and for whom we have lived our lives, and in whose care we are most likely to experience our final days. Preparing for this time is difficult because decisions have to be made. *Who am I? Who is important in my life? Who do I want near me, or do I want to be alone?*

This workbook provides a series of questions to help you think about your future, make decisions, and communicate them to your loved ones and those whom you will choose to act for you if you cannot speak for yourself. You may want to complete this book alone, before you have a caring conversation. Or you may choose to fill it out with someone during a caring conversation. But even if you have already shared these thoughts, we urge you to talk about them again from time to time. Caring conversations affirm life; they ensure that your values and preferences will be known, remembered, and honored.

As you consider the following questions imagine that you are in the last six months of your life. Use additional paper as needed and skip any questions you are not ready to answer.



- With whom do you want to have caring conversations? _____

- What do you most want to say to them? _____

- When and where will you have your caring conversations? _____

- What life events have given you the most joy?

- What life events have saddened you the most?

• What beliefs do you hold that influence your thoughts about life and your thinking about dying? _____

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

• What are your fears regarding the end of your life?

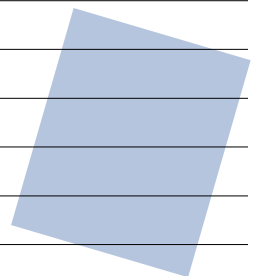
• What do you most value about your physical or mental well being? (Do you love to be outdoors? Does being able to read or listen to music bring you pleasure? How important is it to be aware of your surroundings and the people with you? How important is seeing, tasting, touching?)

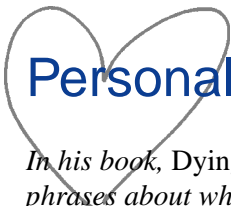
• Are there circumstances under which you would refuse or discontinue treatment that might prolong your life? If so, describe those circumstances.

• If you could plan it today, what would the last day of your life be like? (Where would you be? What would you be doing? What would you eat? What music would you listen to? What would be your final words and your last acts?) _____

• How do you want to be remembered? _____

• If you wrote your own epitaph or obituary, what would it say? _____





Personal/Relationships

In his book, Dying Well, Ira Byock suggests five phrases about which dying people want to have caring conversations. They are "I forgive you. Please forgive me. I love you. Thank you. Good-bye." Consider these phrases as you answer the following questions.

- Are there people to whom you want to write a letter or for whom you want to prepare a taped message, perhaps marked for opening at a future time? _____

- Are there special ways you want to share time with friends and family? (Do you, for example, want to have a private good-bye visit with some of the special people in your life?) _____

- Would you want to make a final trip to visit family, friends, or a special place? (If so, where would you go? What would you do? With whom would you go?) _____

- Do you want to have a special ritual gathering such as a prayer service, perhaps sharing memories or songs? _____

- What are your thoughts about your memorial service? (Do you have any favorite songs or readings? Are there specific people you hope will participate?) _____

Spiritual/Religious Values

- How would you describe your spiritual or religious life? _____

- What gives your life its purpose and meaning? _____

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

- If forgiveness is important to you, how will you seek it, and from whom? _____

- What do you need for comfort and support as you journey 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?)

Healthcare Decisions

- Who would you want to make healthcare decisions for you if you could not make them for yourself? What is his or her relationship to you?

- Who would be your second choice?

- Where do you want to be and what things do you need to be comfortable as you die? (Would you like to be in a hospital, a special place, or at home? Is it important to have sunlight or fresh breezes? To be free of uninvited guests? To be held? To be alone? To review family traditions? To listen to music?)

- Would you want to be sedated if it were necessary to control your pain? _____

- If you could no longer swallow, would you want tube feedings? _____

- Would you want to have a hospice team or other palliative (i.e., comfort) care available to you?

- Would you want treatments that might prolong your life if you were . . . (circle your response)

No longer able to think for yourself?

Yes No

Comatose and not likely to regain consciousness?

Yes No

Terminally ill or near death?

Yes No

Of very advanced age?

Yes No

Career and Work Decisions

- What does “very advanced age” mean to you?

- Do you wish to donate your organs and tissue?

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

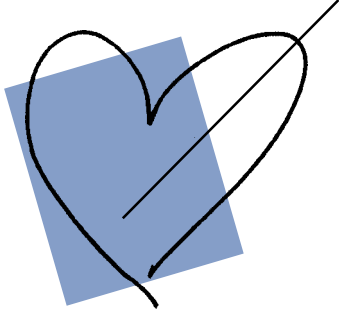
- Would you agree to an autopsy? _____

- Do you prefer burial or cremation? _____

- Goals to be achieved _____

- Duties to be delegated _____

- Projects to be finalized _____



Legal Documents

- Documents to be prepared (e.g., wills, trusts, powers of attorney, healthcare directives)

- Documents to be shared with others (e.g., bank account and safety deposit box information, insurance policies, stock certificates, deeds, titles)

- Providing for your dependents _____

- Making charitable contributions _____

Financial Matters

- Transferring property _____

- Meeting financial obligations _____



Conclusion

Having caring conversations can provide confidence and peace of mind to those faced with making decisions for loved ones at the end of life.

The next section of this workbook includes an advance directive document for your use. It is a legal document that is valid in any state as long as it is notarized, signed, and witnessed. We encourage you to complete this form and give copies to your healthcare provider and family members.

We also encourage you to continue having caring conversations. Your preferences and wishes may change over time, but making your desires known will give you and your loved ones peace of mind as you near the end of life.

Preparing an Advance Directive

Advance directive is a general term used in this workbook to describe both a Healthcare Directive and the Durable Power of Attorney for Healthcare Decisions. It is a term 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 after you have lost the capacity to make or communicate your own decisions. Since 1991, 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. State laws also authorize you to name a person to make healthcare decisions for you when you cannot.

This advance directive has been developed to help you document your wishes about healthcare. It has two parts:

1. Healthcare Directive: a document that allows you to state in advance your wishes regarding treatments that may prolong your life, and
2. Durable Power of Attorney for Healthcare Decisions: a document that allows you to name a person to make healthcare decisions for you.

These documents are intended to ensure that your wishes will be known and followed. They will be more helpful and informative if you discuss your wishes with your family, friends, and healthcare providers as part of your advance care planning. These documents become effective *only when* you can no longer make or communicate decisions for yourself.



The Benefit of Communication

The greatest benefit of your advance directive is its power to communicate your wishes. Discuss your advance directive with your doctor, and make your wishes about healthcare known to family, friends, clergy, your attorney (if you have one), and others who may carry out your wishes.

Completing the *Caring Conversations* workbook first will make this process easier. It provides an opportunity for you to identify and communicate your goals and values. Discuss the workbook information with those who care for you.

Frequently Asked Questions about Advance Directives

1. How is your Healthcare Directive different from a living will?

The Healthcare 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 the use of life-prolonging treatment. A difference is that most living wills apply only when you are terminally ill; the Healthcare Directive becomes effective whenever you lose your ability to make and communicate decisions.

2. Do I need both a Healthcare Directive and a Durable Power of Attorney for Health Care Decisions?

While it is useful, it is not necessary to have both. Because healthcare is complex, situations may arise that your Healthcare Directive does not cover. To anticipate such events, you should name a person (agent) you can trust to make decisions for you. Be sure to discuss your *Caring Conversations* workbook (if you have one) and your Healthcare Directive with your agent.

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

Powers of attorney usually address business and financial matters, and are no longer in effect when you lose decisional capacity unless they are “durable.” 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 you lose the ability to make or communicate your own decisions. Some people choose to name separate agents for business and healthcare decisions and must use separate docu-

ments to do so. This document addresses healthcare matters only.

4. Whom should I name as my agent?

It is important that you 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, but it is not necessary to do so. You might choose your spouse, an adult child, or a close friend. Be sure to talk with your agent about your wishes in detail and confirm that he or she agrees to act on your behalf. If you have completed a *Caring Conversations* workbook, share it with your agent.

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

Your living will may not be as comprehensive as the Healthcare Directive, and may not allow you to name an agent. If you decide to complete the Healthcare Directive and/or Durable Power of Attorney for Healthcare Decisions, notify persons to whom you have distributed your living will and give them a copy of your new advance directive. It is always a good idea to review any previously completed documents and discuss any needed changes with your healthcare providers.

6. Do I need an attorney to make a Healthcare 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 from state to state, however, and from document to document. States typically require witnessing by two adults, and they may limit who may witness. Some states disqualify persons as witnesses who are related to you, who will inherit from you, or for whom you are financially responsible. Because of state-to-state differences, it is a good idea to have advance directives both witnessed and notarized.

8. What do I do with my advance directive after I've completed it?

- 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).
- Discuss the details of your advance directive with these individuals.
- Ask your physician to make it part of your permanent medical record.
- Whenever you are hospitalized, take a copy with you.

9. 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. Your advance directive goes into effect *only when* you are no longer able to make or communicate your decisions.

10. How long will my advance directive be effective?

Your advance directive is effective until the time of your death. It is recommended that you review your advance directive periodically, especially when there is a change in your health status. Each time you review it, redate and initial it, and discuss any changes with your family, friends, and physician.

11. May I change or revoke it?

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

12. 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.

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

Yes, you should expect that your directions will be carried out. Healthcare providers have both legal and ethical duties to respect patient directions, whether verbal or written, within any limitations

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Healthcare Directive

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

I, _____, SS# _____ want everyone who cares for
(please print)
me to know what healthcare I want **when I cannot let others know what I want.**

I always expect to be given care and treatment for pain or discomfort even when such care might make me sleepy, make me feel like not eating, slow down my breathing, or be habit-forming.

I want my doctor to try treatments that may get me back to an acceptable quality of life, with the understanding that treatment will be withdrawn if my condition does not improve to a quality acceptable to me. By an "acceptable quality of life," I mean living in a way that lets me do the things that are important and necessary to me. Those things are

- | | | | |
|--------------------------|-------------------------------|-----------------------|---------------|
| Examples: the ability to | • recognize family or friends | • make decisions | • communicate |
| | • feed myself | • take care of myself | |

I want to have a natural death; therefore, I direct that no treatment (including food or water by tube) be given just to keep me alive 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 there is no reasonable hope that I will regain a quality of life acceptable to me (as described above).

However, in these conditions, I **would** consent to

- | | | | |
|-----------|-------------------------|----------------|----------------|
| Examples: | • resuscitation (CPR) | • dialysis | • ventilator |
| | • food or water by tube | • chemotherapy | • transfusions |
| | • surgery | • antibiotics | |

I also want _____

- | | | | |
|-----------|-----------------------|----------------|------------------|
| Examples: | • to donate my organs | • hospice care | • to die at home |
|-----------|-----------------------|----------------|------------------|

Please refer to my *Caring Conversations* Workbook which is located _____.

■ **Be sure to sign this form on the reverse side of this page** ■

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

Talk about this form and your ideas about your healthcare with the person you have chosen to make decisions for you, your doctor(s), family, friends, and clergy, and 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 _____

This document is provided as a service by Midwest Bioethics Center, the Kansas City Metropolitan Bar Association, and the Metropolitan Medical Society of Greater Kansas City.

Durable Power of Attorney for Healthcare Decisions

It is important to choose someone to make healthcare decisions for you when you cannot. **Tell the person (agent) you choose what you would want.** The person you choose has the right to make any decision to ensure that your wishes are honored. If you **DO NOT** choose someone to make decisions for you, write **NONE** on the line for the agent's name.

I appoint the person named below to be my agent to make healthcare decisions for me when and only when I cannot make decisions or communicate what I want done. This is a Durable Power of Attorney for Healthcare Decisions and the power of my agent shall not end if I become incapacitated or if there is uncertainty that I am dead. This revokes any prior Durable Power of Attorney for Healthcare Decisions. My agent may not appoint anyone else to make decisions for me. I and my estate hold my agent and my caregivers harmless and protect them against any claim based upon following this Durable Power of Attorney for Healthcare or my Healthcare Directive. My agent shall not be responsible for any of these costs. I grant to 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. In exercising this power, I expect my agent to be guided by my directions as stated in my Healthcare Directive (*see reverse side*). My agent is also authorized to

- Consent, refuse, or withdraw consent to any care, treatment, service, or procedure (including artificially supplied nutrition and/or hydration/tube feeding) used to maintain, diagnose or treat a physical or mental condition;
- 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, and review 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 for the purpose of complying with my Healthcare Directive or the decisions of my agent;
- Take legal action, if needed, to do what I have directed;
- Make decisions about autopsy and organ donation, and the disposition of my body; and
- Become my guardian if one is needed.

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

Agent's name _____ Phone _____

Address _____

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

First Alternate Agent

Name _____

Address _____

Phone _____

Second Alternate Agent

Name _____

Address _____

Phone _____

SIGN HERE for the *Durable Power of Attorney* and/or *Healthcare Directive* forms. Many states require notarization. Please ask two (2) persons to witness your signature who are not related to you or financially connected to you or 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 _____

Frequently Asked Questions

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of state law. Your directive is more likely to be honored if you have discussed it with your family and those who care for you, and have named an agent to act on your behalf. If your directive is not being honored, your agent or family should ask for help from the ethics committee.

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

Probably not. However, after the emergency situation has passed, you should expect treatments that you have stated you do not want to be withdrawn or withheld.

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

No, a separate document called a Do Not Resuscitate order (DNR order) is necessary. To get a DNR order, call your local emergency medical provider.

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

Advance directives and decisions made by an appointed agent are morally and legally binding. In practice, however, they are sometimes overridden. The best assurance that they will not be overridden is conversation about these matters with your family and healthcare providers.

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

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

18. May I request that artificially administered food and water (e.g., tube feedings) be withheld or withdrawn?

Yes. A clear and specific request in your advance directive should be honored, and may be required in some states.

19. May I state my wishes for donating organs or tissues in my advance directive?

Yes. You may also want to complete an organ donor card, and discuss your wishes with your family.

20. How can I describe what an “acceptable quality of life” means to me?

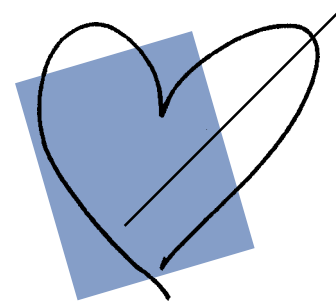
When completing an advance directive think about what you personally mean by “acceptable quality of life.” There is no single “right” answer to this question. However, here are some questions to consider in determining what quality of life means to you.

- Do religious values influence your treatment decisions? (If so, how?)
- How important is it for you to be able to care for yourself?
- What kind of living environment would you be willing to accept?
- How important is it to you to be able to recognize family and friends?
- What is your own “bottom line”? Under what circumstances would dying naturally be preferable to sustaining life?

You are encouraged to complete the *Caring Conversations* workbook and to have conversations to clarify your preferences with those who care for you.

When you have completed your *Caring Conversations* workbook, indicate that you have done so in the “acceptable quality of life” section of your advance directive.

The time you take now to express your choices regarding end-of-life care will give you and your loved ones peace of mind.





The vision of Midwest Bioethics Center, a nonprofit organization founded in 1984, is to create and sustain an environment in which decisions related to human health are based on respect for persons and informed by an understanding of ethics.

The mission of the Center, a membership organization, is to promote ethical decision making in health care by citizens, professionals, and organizations.

We welcome your interest in Midwest Bioethics Center and the *Caring Conversations* program. For more information please contact the Center at (816) 221-1100, visit our website <www.midbio.org>, or email us at <bioethic@midbio.org>.

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place
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here.*