

Conversations That Light the Way



*A Document to Guide Advance Care
Planning and Make Your Wishes Known*

A Letter to All Ohioans

Dear Citizens of Ohio,

This document has been created to assist you in making choices about the kind of health care you want as you journey through the final phases of life. Although this subject can be uncomfortable for many people to address, it is important that each person has the opportunity to make these important choices for himself or herself.

Sometimes, individuals are asked to make health care decisions for loved ones who are unable to communicate their wishes. If you haven't talked with your loved ones about your personal preferences, this situation can be very stressful. On the other hand, when these choices have been discussed, family members can make decisions with greater certainty and comfort.

Having these "courageous conversations" with family members and others can actually be a gift to them and relieve them of the burden of trying to imagine what you may want. You can Light the Way for your loved ones. In beginning these discussions, some people have found it helpful to:

- Take advantage of TV programs that highlight themes of death and dying and talk about your reactions.
- Utilize related news and magazine articles to bring up the subject and talk about what you would want if you were the person in the story.
- Cite an event or experience that will open up the conversation, (such as a relative's or friend's health situation or death). Talk about choices that the person made or didn't make.
- Talk about end-of-life choices while you're completing other legal documents or making financial plans.

The pages that follow contain questions, prompts, and information that are designed to help you think and talk about your choices. You may want to revisit this workbook over the years as these conversations take time and your decisions and choices may change. Further assistance can be obtained by referring to the resources listed at the end of this booklet.

We hope you'll use this document as a tool to help you think about your choices. Fill it out and use it to help you talk to your family and friends.

Sincerely,

The Ohio End of Life Collaborative 2003

Midwest Center for Home Hospice & Palliative Care Education is a 501c3 organization that maintains the brochure "Conversations That Light the Way." The organization's mission is to be the cornerstone for education and technical information about home care, hospice and palliative care provided to the public and professional community.

What If? Health Care Scenarios

- *What if you have been diagnosed with Alzheimer's and are having difficulty remembering things and concentrating. In addition, you have a history of heart disease and have had two heart attacks in the last six years. In the event you have another heart attack, what might your thoughts be about cardiopulmonary resuscitation (CPR)? (Please refer to glossary for more information on CPR.)*
- *What if you have a long-term lung disease that has resulted in repeated trips to the Emergency Room of your local hospital. Each time you have survived, but each trip has required longer stays in the hospital. You are no longer able to drive or care for yourself alone at home. If you were to develop a severe crisis like a life-threatening infection, would you want to get antibiotics through your veins or have surgery?*
- *What if you had a stroke that has left you unable to walk, talk, or live alone. You are having more difficulty swallowing and your loved ones are faced with a decision about whether to begin giving you food and water through a tube into your stomach. What would you want them to do for you?*
- *What if you have been diagnosed with cancer of the pancreas and it has spread to the liver. Your doctor has told you this condition is nearly always fatal. If you were to get pneumonia, would you want to be treated with drugs through your veins to try to cure the infection? Or would you prefer the focus switch from cure to keeping you comfortable even if the infection were to worsen?*

Possible Questions to Ask

- What are the possible benefits compared with the possible risks of the treatment?
- What are the best possible and the worst possible outcomes?
- What is your “bottom line” as you think about the “big picture” and the possible effects on the quality of your life?
- Will the treatment make your life better or merely keep you alive longer?
- What may happen if you refuse the treatment?
- Are there any other treatment choices?

In all of the examples, when would you want the goals of your care to shift from trying to keep you alive, (aggressive curative), to keeping you comfortable and out of pain, (providing comfort and symptom management only) and allowing natural death to occur?

Questions to Guide Conversation

The questions that follow, and your answers to each of them, should be shared with the agent you name in your health care power of attorney document (see page 7).

☼ How would you describe your overall health today?

☼ If you are currently diagnosed with a very serious or possibly life-threatening disease, what do you know about the disease or the progression it may take?

☼ Are you comfortable with your doctor or health care provider? _____ Yes _____ No
If you checked no, please explain:

☼ Do you see him or her as a “partner” in your health care? Does he/she listen to you? Are you confident that he/she will honor your wishes at the end of your life?

_____ Yes _____ No

If you checked no, please explain:

Questions to Guide Conversation

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

 - ☀ What beliefs do you hold that influence your thoughts about life and your thinking about dying?

 - ☀ What important needs would you want to be addressed if you were dying?

 - ☀ What do you value most 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? How important are seeing, tasting, touching?

 - ☀ If you have a memory of a loved one's death, what did you learn from that experience?

Questions to Guide Conversation

☼ How important is it for you to be able to care for yourself?

Very Important Somewhat Important Not Important

☼ What kind of living environment would you be willing to accept?

Assisted Living Private Apartment Nursing Facility
 Retirement Village Extended Care Facility

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

For example: Do religious values influence your treatment decisions? If so, how?

☼ Would you want treatments that might prolong your life, (for example, tube feeding if you could no longer swallow), if you were:

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

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

☼ What special instructions, if any, do you have regarding the above questions?

Questions to Guide Conversation

Choosing a Health Care Advocate

The person you name as an advocate (or, in legal terms, “agent”) in your **health care power of attorney** document has the authority to make decisions regarding aspects of your medical care if you become unable to express your wishes. For this reason, you should tell the person you name how you feel about life-sustaining treatment, being fed through feeding and fluid tubes, and other important issues.

Important:

- *A health care power of attorney is NOT a financial power of attorney. If you have named someone (called an “attorney-in-fact”) to handle financial matters for you through a regular power of attorney document, that person cannot automatically make medical decisions for you. If you wish, you may ask the person you’ve named in your financial power of attorney document to also speak for you in health care manners when you cannot speak for yourself. BUT you must separately name that person as your health care “agent” through another document called a health care power of attorney. You will need to complete an official health care power of attorney form and have it notarized or witnessed.*

Think not only about who knows you very well and cares about you, but who can make difficult decisions. Your spouse or family member may be too emotionally involved with you, or sometimes they are the best choice. You decide. Make sure the person, if not local, can be ready to help when you need them. Make certain the person you choose is able to stand up for you so that your wishes are followed. Most importantly, no matter who you choose, make your wishes clear and be comfortable that he or she agrees to honor your decisions.

- ✿ Who would you want to make healthcare decisions for you if you could not make them for yourself? (The person you name here should be the same as the one named in your durable health care power of attorney document.)

List his or her name, address, and phone number(s) here:

- ✿ What is his/her relationship to you?

- ✿ Who would be your second choice?

List his or her name, address, and phone number(s) here:

Questions to Guide Conversation

- ☼ Have you completed your advance directive forms? _____ Yes _____ No
If yes, Where are they located?

MAKING YOUR WISHES KNOWN

It's not enough to just complete a living will and durable power of attorney-health care documents. It is important to have a conversation with your family or friends. The following questions can help you begin this important conversation with those you love. Write your responses here, talk with your family, and put this document and your advance directives in a safe and known place after you have copied and distributed them to your physician(s) and family members or friends. (Because these documents may be needed quickly, a safe deposit box at a bank is not the best location.)

- ☼ Would you want to be sedated, kept in a sleeping state, if it were necessary to control your pain?

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

Questions to Guide Conversation

☼ If you could plan today, what would the last day of your life be like?

For example: 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 acts? Who would be with you?

Questions to Guide Conversation

☼ Would you want to have a hospice team or other palliative (comfort) care available to you to ensure effective pain control and relief from any distressing symptoms like shortness of breath, nausea, etc.?

☼ Do you fear any particular treatments or procedures? _____ Yes _____ No

If you checked yes, list the treatments or procedures:

☼ What are your fears or concerns about the end of your life?

☼ Under what circumstances would dying naturally be preferable to sustaining life?

Questions to Guide Conversation

- ☼ What do you need for comfort and support as you journey near death?
For example: Do you want to pray with a member of the clergy or other trusted person? Be read to from spiritual or religious texts? Listen to poetry or music?

☼ Do you wish to be an organ donor? _____ Yes _____ No

☼ Do you wish to include your name in Ohio's organ donor database so that an organ procurement organization can respond quickly to transplant needs?
_____ Yes _____ No

☼ Are there any special instructions?

Important Donation Facts:

- ☼ Your status as an organ donor is considered only after every effort has been made to save your life and you have been declared legally dead.
- ☼ Information provided through the Ohio Donor Registry can be assessed and used only by authorized organ, tissue and eye recovery agencies in Ohio.
- ☼ You may change your mind or refine your decisions at any time, but you must complete and file another Donor Registry Enrollment Form.
- ☼ An open casket is still possible. The recovery of organs and tissues is a surgical procedure that ensures the donor's body is treated with dignity and respect.

To complete a Donor Registry Enrollment Form, please see your local auto license bureau or use the form included in Choices: *Living Well at the End of Life*, at:
www.midwestcarealliance.org under Public, Advance Directives.

Glossary

Advance Directives

documents, including the Living Will, Durable Health Care Power of Attorney and Mental Health Declaration, that allow an individual, “in advance,” to directly convey his or her wishes about health care treatment, or to choose someone to convey those wishes to medical personnel if the individual is unable to speak for himself or herself

Antibiotics

drugs used to fight infection

Artificial nutrition and hydration

using tubes or intravenous (IV) lines to supply food or water and other fluids when a person is unable to eat and drink

CPR (Cardiopulmonary resuscitation)

a medical procedure using such treatments as external chest compression, administration of drugs, and/or electric shock treatment in an effort to restore the heartbeat

Dialysis

the use of a machine to cleanse the blood when the kidneys are not functioning normally

Donor Registry Enrollment Form

a form that allows you to register your name with the Bureau of Motor Vehicles as an organ, tissue and/or eye donor, and to specify the organs or tissues you wish to donate, and the specific purposes for which they can be used

DNR (Do Not Resuscitate)

a physician’s order that advises health care providers how to proceed if a person’s heart or breathing has stopped.

DPOA-HC (Durable Power of Attorney for Health Care or “Health Care Power of Attorney”)

a legal document that authorizes another person to make health care decisions for you if you are unable to make informed health care decisions yourself

Hospice

a program of care that addresses the physical, emotional and spiritual needs of patients facing end-of-life, as well as those who care for them

Life Supporting Technologies

any medical procedure, treatment, intervention or other measure that, when administered, serves principally to prolong life

Living Will

a document that contains your written wishes for care at the end of life. Through it, you can state your preferences regarding aggressive, life-prolonging treatment

Glossary

Mental Health Declaration

allows you to state your own preferences regarding your mental health treatment and to designate an individual to make mental health care decisions for you when you are unable to make these decisions for yourself (The health care power of attorney covers mental health concerns for most people, but those who have been diagnosed with a mental illness may wish to have this document as well.)

Palliative Care

focuses on comfort care for body, mind and spirit

Ventilator

a breathing machine attached to a tube that is placed in a person's windpipe when he or she is unable to breathe normally

Advance Directives Packet

The Advance Directives Packet, **Choices: Living Well at the End of Life**, contains:

- Your Questions Answered
- Ohio's Living Will
- Ohio's Living Will Declaration Form
- Ohio's Health Care Power of Attorney
- Ohio's Health Care Power of Attorney Form
- Ohio's Do-Not-Resuscitate Law
- The Hospice Choice
- Organ & Tissue Donation
- Donor Registry Enrollment Form

To receive **Choices: Living Well at the End of Life**:

- Visit www.midwestcarealliance.org and download the packet at no cost
- Send \$3 for the printed **Choices: Living Well at the End of Life** to:

**Midwest Center for Education
855 South Wall Street
Columbus, Ohio 43206**

- Call 1-800-776-9513 for additional information

**Midwest Center for Education is an affiliate of Midwest Care Alliance*

Resources

Books:

- Baines, Barry.** Ethical Wills: Putting Your Values on Paper, Cambridge, MA: Perseus Books, 2001.
- Byock, Ira.** Dying Well, New York: Riverhead Books, 1997.
- Byock, Ira.** The Four Things That Matter Most, New York: Free Press, 2004.
- Callahan, Daniel.** The Troubled Dream of Life: In Search of a Peaceful Death, New York: Simon & Schuster, 1993.
- Callanan, Maggie.** Final Gifts, New York: Bantam Books, 1992.
- Dunn, Hank.** Hard Choices for Loving People, Herndon, VA: A & A Publishers, Inc., 1992.
- Lattanzi-Licht, Marcia.** The Hospice Choice: In Pursuit of a Peaceful Death, New York: Simon & Schuster, 1998.
- Lynn, Joanne.** Handbook for Mortals: Guidance for People Facing Serious Illness, New York: Oxford University Press, 1999.
- Tobin, Daniel.** Peaceful Dying: The Step-by-Step Guide to Preserving Your Dignity, Your Choices, and Your Inner Peace at the End of Life, Reading, Mass.: Perseus Books, 1999.
- Webb, Marilyn.** The Good Death: The New American Search to Reshape the End of Life, New York: Bantam Books, 1997.

Websites:

www.aarp.org

provides comprehensive information and services for seniors, information about support groups and various publications

www.growthhouse.org

provides information about life threatening and terminal illnesses, hospice and home care, pain management, palliative care, death, and bereavement

www.nhpco.org

National Hospice & Palliative Care Organization

www.ohpco.org

Ohio Hospice & Palliative Care Organization (Download Ohio Advance Directives packet here.)

www.caringinfo.org

information about end of life issues and decision making

www.pbs.org/wnet/onourownterms/index.html

provides information about decision making and end of life care based on the PBS series

www.ohiobar.org

Provides pamphlets explaining living wills, health care powers of attorney, and DNR; go to "search" box and type in "LawFacts"

www.osbf.net/advancedirectives/index.htm—awareness campaign for Ohio's Advance Directive Packet

***For more information on receiving Advance Directive Forms,
visit www.midwestcarealliance.org or call 1-800-776-9513.***

Ohio End of Life Collaborative

Partners:

American Cancer Society, Ohio Division
Findlay Area End of Life Coalition
HomeReach Hospice
Hospice and Palliative Care of Greater Wayne County
Hospice of the Western Reserve
Hospice of Central Ohio
LeadingAge Ohio
Marietta Memorial Hospital, Respecting Choices Committee
Midwest Care Alliance
Office of the State Long-Term Care Ombudsman
Ohio Department of Health Cancer Program
The Ohio State Bar Foundation

Contributing Agencies:

Advance Care Planning Coalition of Greater Toledo	Ohio Attorney General's Office
Bridge Home Health & Hospice	Ohio Council for Home Care
Catholic Healthcare Partners	Ohio Funeral Directors Association
Central Ohio Area Agency on Aging	Ohio Health Care Association
Central Ohio Hospice & Palliative Care Nurses Association	Ohio KePRO
FAMILIES FOR IMPROVED CARE	Ohio Nurses Association
Good Samaritan Hospital	Ohio Osteopathic Association
Hospice & Palliative Care of the Visiting Nurse Service	Ohio State Bar Association
Hospice of Cincinnati	Ohio State Medical Association
Licking County Honoring Choices at the End of Life	Robinson Visiting Nurse & Hospice
Licking Memorial Hospital	State of the Heart Home Health & Hospice
Mount Carmel Hospice & Acute Palliative Care Service	Stein Hospice Service
	Working Group to Improve Psychosocial Care Near the End of Life

Credits

Caring Conversations

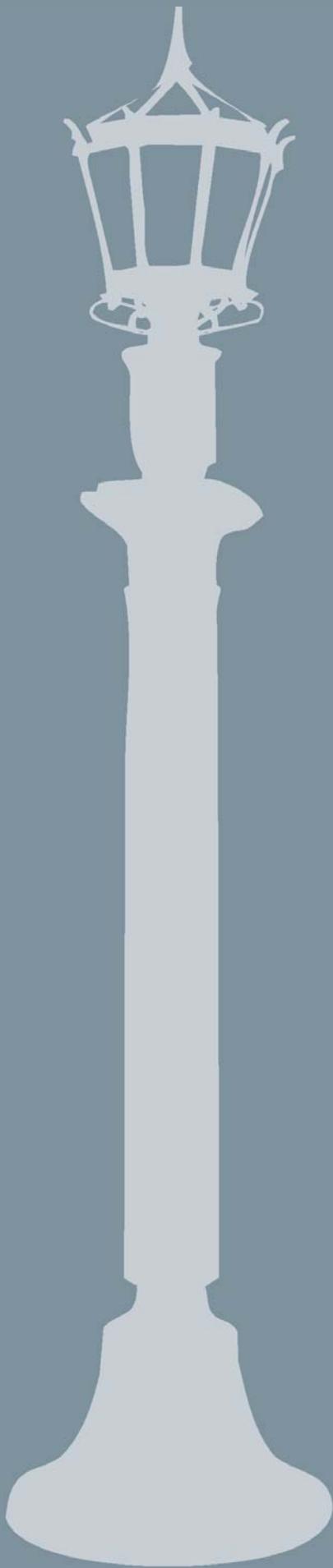
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Center for Practical Bioethics, Kansas City, MO, 1999

Conversations Before the Crisis

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Last Acts, Washington DC, 2003

“Isn’t it Time We Talk?”

Printed with permission from
The Carolinas Center for Hospice and End of Life Care, 2003



For more information:

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www.midwestcarealliance.org