



WESTERN
RESERVE
CARE SOLUTIONS

Courage in Conversation

Communicating your goals of care
and healthcare choices in Ohio



HOSPICE OF THE
WESTERN RESERVE



Stein
Hospice

AN AFFILIATE OF HOSPICE OF THE WESTERN RESERVE



HOSPICE OF THE
WESTERN RESERVE

at



University Hospitals

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Foreword

Most people avoid thinking about their own death except in practical terms. It's easiest to concentrate on material things; what to do with the house, car or valuables. If there is wealth to distribute, estate planning can be very complicated. Many of us only need a simple will.

However, the goal of healthcare planning for end-of-life is virtually same for everyone, regardless of financial status. The vast majority of people want the same experience at the end of life and for their dying. When encouraged to think about their own end-of-life, Americans report that **they do not want to be: alone; afraid; in pain; intubated; ventilated or resuscitated.** In short, they want to be peaceful and comfortable.

Most people are also very clear that they want to die at "home." Not in a hospital but in a comfortable, familiar place, surrounded by their loved ones. The unfortunate reality is that 70% of Americans die somewhere other than home.

If most people wish to die at home, why do so many of us pass away in hospitals?

Often, it is because there is a lack of planning, and talking, about end-of-life healthcare. National polls indicate that people believe their loved ones will make sure their end-of-life choices will be honored. At the same time, fewer than 15% have ever discussed those choices with anyone!

All of us at Hospice of the Western Reserve strongly support the development of **advance directives** — living wills, durable powers of attorney for healthcare and organ donation enrollment, if desired. These tools are important but alone are not enough to ensure your healthcare choices will be followed if you are unable to speak for yourself. In addition to the legal documents, it is vital that you appoint agents (advocates) who you trust implicitly and who understand your wishes regarding end-of-life care.

Agents can be family members, friends or professionals such as attorneys or, sometimes, healthcare providers. Agents must be identified in and authorized through the advance directives documents. But that is the final step. Before identifying your agents in writing, you must have an open and honest conversation so that all involved are confident about their roles in fulfilling your end-of-life choices.

Death and dying are inescapable realities. The people who love you the most and who you trust to act as your agent, may be the most uncomfortable discussing your end-of-life choices. Although dying is an uncomfortable topic, there is a good time to bring it up and that is **long before an urgent decision is needed.** Talking about how we want to live as we approach death, and communicating our wishes for end-of-life care while we are not dying, will ease the strain for our loved ones. Future peace of mind is a gift you can give them right now.

This booklet has been created to guide you as you have end-of-life conversations with your loved ones. It also contains helpful resources and State of Ohio Advance Directive forms—legal documents that are ready to complete.

Do not construe this document as legal advice. Seeking counsel is not required, but you might consider consulting an attorney as part of the process.

Frequently Asked Questions

Many doctors' offices and clinics are now posting signs that ask "Have you completed your advance directives?" and your physician may ask you the same question. But what exactly are "Advance Directives?"

Q: What Makes Up "Advance Directives?"

A: Written advance directives help others accurately remember your healthcare choices and goals of care. They consist of:

- ◆ **Healthcare Power of Attorney:** you appoint an agent to make healthcare decisions for you if you are unable to speak for yourself. This does not apply to finances.
- ◆ **A Living Will:** provides a narrow set of instructions about care at the end of life.
- ◆ **Organ Donation Enrollment:** optional.

Many people assume that their financial power of attorney can make healthcare decisions for them. That is not true. It is necessary to appoint a specific agent, a Healthcare Power of Attorney, to make healthcare decisions on your behalf, if you are unable to speak for yourself. He or she may or may not be the same individual as your financial power of attorney. If you are not able to communicate due to serious injury or illness your loved ones will need to rely on the instructions that appear in your Advance Directives. And, if you have had open conversations with your agent and your loved ones, everyone should be aware of your choices.

But remember, as long as you are capable of making your own decisions, you remain in control of your own medical care. Only in the event that you are unable to speak on your own behalf, your advance directives would guide decision making.

Q: If I have a Healthcare Power of Attorney, do I need a Living Will too?

A: Yes. Most people want to have both documents because they can address different aspects of your medical care. A Living Will allows you to state your wishes regarding life-sustaining medical treatments if you are at the end of life and unable to communicate. A Healthcare Power of Attorney gives you the opportunity to

appoint someone you trust to make medical treatment decisions for you in the event you are unable to make or communicate them yourself.

Q: Who should I choose as my agent?

A: Choose someone you trust. They may be a family member, close friend or professional advisor. It is important that he or she understands your choices and is willing to act as an advocate on your behalf.

Q: Is it possible to request that food and water administered by IVs (intravenous tubes) be withheld or withdrawn?

A: Yes. In your Living Will you can state a specific request to have artificially administered food withheld or withdrawn.

Q: How can I address organ donation in my advance directives?

A: You may state your wishes in the document. You also need to complete an organ donor enrollment card. Be sure to share this request with your loved ones. And inform the State of Ohio BMV so your drivers' license or state ID can be marked.

Q: What other documents might I need?

A: Financial planners and estate planning attorneys recommend completing financial documents such as trusts, last will and testament and financial power of attorney. Hospice of the Western Reserve also works with the community and our patients to complete Ethical Wills and Legacy Letters which are personal documents that can be passed to your loved ones.

Q: When can I change my advance directives? How long is it effective?

A: You may change or revoke your documents at any time. It is recommended that you review the forms when you have a change in your health or life status, such as a life threatening diagnosis or a divorce. Documents are effective for your lifetime unless you change or revoke them.

Q: Where should I keep my advance directives?

A: You should keep your documents in a safe place, making certain your loved ones know where you stored them. Make copies for the agent(s) named in your Healthcare Power of Attorney and other key individuals in your life (i.e., physician, clergy, attorney, loved ones). Have your physician make the forms part of your permanent medical record. Some people, if they are able, choose to bring a copy with them when they are hospitalized. Most hospitals will ask if you have completed advanced directives upon admission.

Q: What if I choose not to complete my advance directives?

A: You put others in the uncomfortable position of making decisions for you, without the knowledge of knowing what you would have wanted. Your healthcare choices may be unknown and unfollowed.

If you are reading this booklet because you or a loved one has been diagnosed with a serious illness, the following is information regarding hospice care.

Q: What is Hospice Care?

A: Hospice is compassionate, comfort-oriented care for the seriously ill with an emphasis on pain management, symptom control and spiritual and emotional support for the patient and loved ones. A patient qualifies for hospice care when a prognosis of weeks or months, rather than years, to live has been made. Hospice is not a place, it is a philosophy of care. Hospice of the Western Reserve is one of many hospice care providers in northern Ohio. Care should be sought soon rather than later in the course of a serious illness—not just the last days or weeks of life—to benefit from the full realm of services including:

- ◆ 24-hour telephone access to services and support
- ◆ Pain management and symptom control
- ◆ Medical equipment, tests, procedures, medications and treatments necessary to make our patients comfortable
- ◆ Nursing care; experts to help loved ones acclimate to the role of caregiver
- ◆ Counseling and social work services

- ◆ Expressive therapies, including art and music therapy for patients and family members
- ◆ Massage therapy for patients and family members
- ◆ State-tested nursing assistants to help with personal care
- ◆ Volunteer supportive visits
- ◆ Spiritual care
- ◆ Palliative care for those not ready for hospice care
- ◆ Bereavement services for more than a year following the loss of a loved one

The following are questions you should ask any potential hospice care provider AND answers pertaining specifically to Hospice of the Western Reserve.

Q: How long has the hospice been providing care in our community?

A: Hospice of the Western Reserve has been a part of Northern Ohio for over 45 years.

Q: Is the hospice staff hospice and palliative care certified?

A: Hospice of the Western Reserve has the most certified staff in the region.

Q: If I need to go into a hospital or nursing home, which ones work with the hospice? Where would the hospice admit your loved one if there was a need for hospitalization?

A: Hospice of the Western Reserve has more than 300 contracts with area hospitals and nursing facilities.

Q: Does the hospice own or operate an in-patient care facility to provide home-like care in a hospice residence?

A: Hospice of the Western Reserve owns and operates four inpatient campuses. Ames Family Hospice House in Westlake, David Simpson Hospice House on Cleveland's lakefront, Medina Hospice Inpatient Unit near I-71, and Stein Hospice Inpatient Unit in Sandusky.

Q: In a crisis, will staff come to the home at any time, day or night? What about holidays and weekends? Are they available 24 hours a day, 7 days a week?

- A:** Hospice of the Western Reserve provides:
- ♦ A dedicated crisis team that provides continuous care (a Medicare level of care) and will visit where the patient resides, whether it is a residential home, assisted living or nursing facility to provide care during a pain or symptom crisis. To reach this team, call 800.707.8921.
 - ♦ 24/7 - referral/admission team to admit patients, with same day openings.
 - ♦ On-call staff available to meet urgent needs, often with a response time of 2 hours or less.
 - ♦ Administrator on call to respond to your needs: 216.255.9071

Q: Is the hospice nonprofit or for-profit?

A: Hospice of the Western Reserve has been not-for-profit since its beginnings in 1978. We are not beholden to shareholders and you can't buy stock in our organization: we answer to the community we serve.

Q: Is the hospice certified by The Joint Commission or Community Health Accreditation Program (CHAP)?

A: Hospice of the Western Reserve is certified by both.

Getting Started

There are a few points to consider as you begin this process:

Planning

Have a plan as to how you will share your wishes. Will you have things written down? Do you want your loved ones to take notes? Who will you share your goals of care and your healthcare choices with?

Environment

Create a comfortable environment that is conducive to listening. Don't try to chat while in the middle of something else. Sit down and be comfortable.

Information

It may be necessary to share your thoughts over several conversations. Be compassionate if your loved one is upset by your honesty but don't apologize for the information you are sharing; these are your choices.

Time

Allow time for your loved ones to process information and respond. This is one of the most important things you can do. They may have questions or feelings to share with you.

Next Steps

Begin to plan your next steps. These may include funeral arrangements, financial arrangements or simply informing your loved ones where your documents are stored.

Sharing your choices through open conversation may be challenging. It is, however, important to be sure your loved ones understand your wishes and are willing and able to speak on your behalf during a difficult time. The more information you provide, the more guidance and comfort they receive and the more certain you can be that your goals of care are met.

Preparing for the Conversation

Defining your wishes for end-of-life care

It is important to give careful consideration for your choices in care. Although not a legal document, use this worksheet to help you define the healthcare choices you want to make and your own goals of care.

1 My Quality of Life

I would like my doctor to try treatments that may restore an acceptable quality of life so that I may do what I feel is important and necessary. On a scale of 1 to 5, with 1 being very important and 5 not important to me, I rate these issues, which define my quality of life:

	VERY IMPORTANT			NOT IMPORTANT	
Being able to recognize my family and friends	1	2	3	4	5
Being able to communicate with them and knowing I am understood	1	2	3	4	5
Having the ability to think clearly	1	2	3	4	5
Being free from pain	1	2	3	4	5
Being free from symptoms most of the time (<i>nausea, diarrhea, shortness of breath</i>)	1	2	3	4	5
Being able to eat and drink	1	2	3	4	5
Being able to control my bladder and bowels	1	2	3	4	5
Being able to live in my own home	1	2	3	4	5

2 My Prognosis

If I was very ill and told there was little chance that I would live much longer, it is important that I be able to:

PLEASE CIRCLE ONE

Continue with all possible treatments in the hope that a miracle might happen to restore my health	Yes	No	Unsure
Be allowed to die with dignity and given medications to alleviate any pain or discomfort I might have	Yes	No	Unsure

If I were in a coma and my doctors thought there was little hope for regaining consciousness, I would like to:

PLEASE CIRCLE ONE

Be kept alive indefinitely in the hope that future medical advancements would restore my health	Yes	No	Unsure
Have all treatment discontinued, and no new treatment started	Yes	No	Unsure

3 Treatments

These are my choices on possible treatments that can be administered if I should have a terminal illness, dementia or serious stroke or in a coma:

PLEASE CIRCLE ONE

Surgery	Yes	No	Unsure
CPR to start my heart or breathing if either should stop	Yes	No	Unsure
Medicine for infections (antibiotics)	Yes	No	Unsure
Kidney dialysis	Yes	No	Unsure
A respirator or ventilator to breathe for me	Yes	No	Unsure
Food or water through a tube in my vein, nose or stomach	Yes	No	Unsure
Blood transfusions	Yes	No	Unsure

4 The End of the Journey

My last days are an important time to say, "I love you" "Thank you" and "Goodbye." On a scale of 1 to 5, with 1 being very important and 5 not important to me, I rate these issues, which define how I would like to spend those days:

	VERY IMPORTANT			NOT IMPORTANT	
	1	2	3	4	5
At home	1	2	3	4	5
In a hospital	1	2	3	4	5
Surrounded by family and friends.	1	2	3	4	5
Free from pain and discomfort	1	2	3	4	5
Being alert, even if I might be in pain	1	2	3	4	5
Having time with my pastor, rabbi, priest or other spiritual advisor	1	2	3	4	5
Having time to address forgiveness, gratitude and love	1	2	3	4	5

Now that you have completed this worksheet, which helps to define your healthcare choices, share your choices with the person(s) you've chosen to be your healthcare advocate as identified in your healthcare power of attorney document, as well as other loved ones and your trusted advisors (medical, legal and financial professionals).

I realize that this is not a legal document, but a tool to help clarify my wishes.

Signature: _____

Date: _____

Preparing for the Conversation

Values & Preferences Checklist

Check the box that best describes how you would feel if you were:	LIFE LIKE THIS WOULD BE:			
	Difficult but acceptable	Worth living, but just barely ^A	Not worth living ^B	Don't know ^C
Unable to walk but able to propel a wheelchair				
Unable to leave home				
In pain most of time				
Uncomfortable most of time (nausea, diarrhea, shortness of breath)				
Depressed or "blue" most of the time				
Fed through a feeding tube				
Needing a breathing machine for each breath, which prevented speech				
Required to have someone around 24 hours daily to care for you				
Unable to control your bladder				
Unable to control your bowels				
Required to live in a nursing home				
Confused and thinking unclearly much of the time				
Unable to recognize family or friends				
Unable to talk and be understood by others				
In a condition that caused your family to feel worried or stressed				
In a condition that caused a severe financial burden on your family				
Other				

^AIf you checked more than one factor, would a combination of these factors make your life "not worth living?" If so, which factors?

^BDoes this mean that you would rather die than be kept alive?

^CWhat information or people do you need to help you decide?

Adapted from Your Life, Your Choices, <http://www.mccl.org/document.doc?id=275>

Glossary of Terms

Advance Directives – A general term that describes legal documents: living wills, medical powers of attorney and organ donation enrollment, as appropriate. These documents allow you to give instructions about your future medical care, your end-of-life choices and appoint a person to make healthcare decisions if you are unable to make them yourself. Each state regulates the use of advance directives differently.

Capacity – In the healthcare context, this denotes the ability of the patient to understand and appreciate the nature and consequences of healthcare decisions affecting their outcomes and to make an informed decision. The term “competent” is also used to indicate ability to make informed decisions.

CPR (Cardiopulmonary Resuscitation) –

A group of treatments, any or all of which are given to support or restore breathing and circulation if the heart or lungs stop working.

DNR (Do-Not-Resuscitate) Order – A physician's written order instructing healthcare providers not to attempt CPR if the patient stops breathing or the heart stops beating. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of the patient or the person speaking on behalf of the patient, it must be signed by a physician to be valid.

DNR Comfort Care (DNRCC) – is a legally-sanctioned program that is implemented according to a standardized protocol. The DNRCC Order is implemented at different points, depending upon the patient's wishes and must be consistent with reasonable medical standards. There are two options within the DNR Comfort Care Protocol:

- ◆ DNR Comfort Care (DNRCC) Order – a person receives any care that eases pain and suffering, but no resuscitative measures to save or sustain life from the moment the order is signed by the physician.
- ◆ DNR Comfort Care-Arrest (DNRCC-Arrest) Order – a person receives standard medical care that may include some components of resuscitation until he or she experiences a cardiac or respiratory arrest.

Healthcare Power of Attorney – A document that allows

individuals to appoint someone else to make decisions about their medical care if they are unable to communicate. It may also be called a “healthcare proxy,” “durable power of attorney for healthcare,” or “appointment of a healthcare agent or surrogate.” The person appointed may be called a healthcare agent, surrogate, attorney-in-fact, or proxy.

Hospice care – Comfort-focused care that includes pain and symptom management and emotional and spiritual support. The circle of care also extends to caregivers and loved ones. With the emphasis on comfort rather than cure, loved ones are able to spend time simply being together. Pain is reduced. Anxiety is relieved. For caregivers, the stress of caring for someone with a serious illness is diminished by having a team of compassionate professionals involved.

Life-sustaining Treatment – Treatments (medical procedures) that replace or support an essential bodily function (may also be called life-support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis and others.

Living Will – A type of advance directive in which people document their wishes about future medical treatment if they are at the end of life and unable to communicate. It may also be called a “directive to physicians,” “healthcare declaration,” or “medical directive.” The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatments.

Palliative care – Specialized care for those who have chronic or serious illness, but not necessarily for those facing end-of-life issues. It includes pain and symptom management and support for patients and families.

Withholding or Withdrawing Treatment – Choosing not to have life-sustaining measures or discontinuing them after they have been in use over time.