

# *From the Start, Consider the Finish*

## A POCKET GUIDE TO DECISION-MAKING



**Authors:** Dr. Sean Marks and Julie Owen

**Faculty Advisor:** Julia Uihlein

**Staff Support:** Diane Kramer

CENTER FOR BIOETHICS & MEDICAL HUMANITIES  
Medical College of Wisconsin

## Let's talk about *Dying*.

### *HOW DO YOU WISH TO DIE?*

If you are like most Americans, you may answer: “very old, at home, suddenly and unexpectedly, while sound asleep.” Unfortunately, statistics suggest that this version of death is not the norm for most individuals. 65% of Americans will die after a prolonged battle with one of two chronic diseases: heart disease or cancer. And 80% of Americans will die—perhaps against their wishes—in a nursing home or hospital.

### *THE PROCESS*

In the context of an incurable, progressive chronic illness, the signs and symptoms of death can be “diagnosed” just as any other disease process or disorder. If, however, these important warning signs are missed, a proper care plan cannot be developed, and the patient ultimately suffers needlessly. These signs and symptoms are collectively referred to as the “Syndrome of Imminent Death”—it is important to note that this collection of signs makes up the **normal process of dying**, and death is typically hours to weeks away when these symptoms begin to appear. Early signs include being bed-bound, decreased intake of food/drink, and decreased mental functioning. Later, the individual will begin to experience increased sleepiness/coma, decreased urine output, fevers, skin changes, delirium/hallucinations, changes in breathing patterns, and impaired clearing of airway secretions, producing a “death rattle” sound when the patient inhales. Again, these signs—though alarming—do not mean that your loved one is feeling pain. These signs are part of the normal dying process.

### *THE STIGMA*

Medical science and technology have advanced at lightning speed in this country. While these advances have obvious benefits, they can also prevent people from facing the reality and inevitability of death. Making a plan for end-of-life care has never been more important.

### **WHEN NO ONE DECIDES...**

What happens when we are unable to speak openly about end-of-life issues? Patients may never know concretely that they are dying. They cannot say goodbye to loved ones. Families are left with the burden of making difficult medical decisions without knowing what they should do, and in the process, they may experience Post-Traumatic Stress and depression. ***The good news: end-of-life planning is quite simple.***

## **PLANNING AHEAD: ADVANCE DIRECTIVES**

### ***IT'S NEVER TOO EARLY***

In 1990, Congress passed the **Patient Self-Determination Act**. This legislation requires any hospitals or health care institutions that receive Medicare reimbursements to inform patients about advance directives. An **ADVANCE DIRECTIVE** is a state legal document, which may seem intimidating. But, it does not require a lawyer to fill out; in fact, you can fill out an advance directive in just a few minutes while in your doctor's office. (And, it's free!)

There are 2 types of Advance Directives. Perhaps most important of the two is the **Health Care Power of Attorney** (also known as a health care proxy, health care agent, etc.). Your Health Care "POA" is a trusted individual whose duty it is to carry out your wishes for care if you happen to be unable to make those decisions yourself when the time comes. This person preserves your autonomy and speaks on your behalf when you cannot. If you don't have one in the state of Wisconsin, decisions are instead made by "family consensus." Needless to say, this can create unpleasant issues. Planning ahead can prevent family conflict when emotions are raw and stress is high.

The second type of Advance Directive is a **Living Will**. This is also a state legal document, and it provides an opportunity to leave your wishes in writing. However, it is only honored when your health situation is deemed "terminal." Also, the document is open to a bit of interpretation.

### **I'VE GOT A HEALTH CARE POA. NOW WHAT?**

It is important that you speak with the person you choose as your health care Power of Attorney (POA) about your end-of-life care wishes. ***Do not assume that they know your wishes, and do not leave those important decisions up to them.***

Remember the game "20 Questions"? Play 20 Questions with yourself to determine your own end-of-life care beliefs. When you have answered these questions, discuss these topics with your health care Power of Attorney so your wishes are clear.

## 20 QUESTIONS

### *Quiz yourself on end-of-life care beliefs*

1. Do you think it is a good idea to sign a legal document that says what medical treatments you want and do not want when you are dying? *This is called a “living will.”*
2. Do you think you want any of the following medical treatments?
  - **Kidney dialysis**—used if your kidneys stop working.
  - **Cardiopulmonary resuscitation**, a.k.a. “CPR”—used if your heart stops beating.
  - **Respirator**—used if you can’t breathe on your own.
  - **Artificial nutrition**—used if you can’t eat food.
  - **Artificial hydration**—used if you can’t eat fluids.
3. Do you want to donate parts of your body to someone else when you die? *This is called “organ donation.”*
4. How would you describe your current health? If you have medical problems right now, how would you describe them?
5. If you have medical problems right now, do they affect your ability to function? If so, how?
6. How do you feel about your current health?
7. If you have a doctor, do you like him/her? *Why? (Or why not?)*
8. Do you think your doctor should make the final decision about any medical treatment you may need?
9. How important is it to you to be independent and self-sufficient in your life?
10. If you lose some of your physical and mental abilities, how would that affect your attitude toward independence and self-sufficiency?
11. Do you expect that your friends, family, and/or others will support your decisions about medical treatment you may need now or in the future?
12. What will be important to you when you are dying (examples: physical comfort, no pain, family members present, etc.)?
13. Where would you prefer to die?
14. What is your attitude toward death?
15. How do you feel about using life sustaining measures if you are:
  - a. Terminally ill?
  - b. In a permanent coma?
  - c. Irreversibly, chronically ill (i.e., Alzheimer’s Disease)?

16. What is your religious background?
17. How do your religious beliefs affect your attitude toward illness, dying, and death?
18. Is your attitude toward death supported by your religion?
19. How does your faith community, church or synagogue view the role of prayer or religious sacraments in an illness?
20. What else do you feel is important for your POA to know?

## CHOICES, CHOICES: PALLIATIVE OR HOSPICE?

Research shows that most patients in America wish to die at home, if possible. Second choice? Hospital. Almost no one wishes to die in a nursing home. However, in this country, the majority of patients do in fact die in a hospital or nursing home; very few die at home.

### *What resources are available to care for a dying person?*

**Hospice care** is an insurance benefit defined by Congress. If you are a Medicare recipient, you may qualify for the hospice benefit if your doctor and the hospice medical director certify that you are **terminally ill** and have **6 months or less to live if your illness runs its normal course**. Hospice can then provide the medical care from professional health care providers, medications, and medical equipment needed for the patient's comfort and related to the terminal disease. **The goal of hospice: comfort.** It is designed to meet a patient's needs so the family can care for the patient until the end.

### *What if I don't have Medicare?*

Most private insurance plans do offer coverage for hospice care, though coverage will vary. Medicaid in Wisconsin generally mimics the Medicare benefit.

### *What if I prefer not to be at home?*

If a patient or family does not wish to be at home through the dying process, or if care at home becomes unmanageable, a hospice team can coordinate a transfer of care to a facility where the patient can receive hospice care.

### *Hospice: Just the Facts.*

- **HOSPICE** provides comfort and support services to people who are terminally ill. It helps them live out the time they have remaining to the fullest extent possible.
- **HOSPICE** care is provided by a specially trained team that cares for the "whole person," including his/her physical, emotional, social, and spiritual needs.
- **HOSPICE** provides support to family members caring for a terminally ill person.
- **HOSPICE** is generally given in the home.
- **HOSPICE** services may include drugs, physical care, counseling, equipment, and supplies for the terminal illness and related conditions.

- **HOSPICE** isn't only for people with cancer.
- **HOSPICE** doesn't shorten or prolong life.
- **HOSPICE** focuses on comfort, not on curing an illness.

### **But what if I'm not ready for hospice?**

**Palliative care** is a type of medical care focused on **providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis.** Many health care institutions, including hospitals and clinics throughout Wisconsin, now offer palliative care programs in which a medical team with extra training and expertise in providing palliative care can work together with patients and families to provide symptom management and support for patients with serious medical diseases. Palliative care teams may include doctors, nurses, chaplains, social workers, and/or psychologists. These palliative care teams work with other doctors to help improve the quality of life for both the patient and the patient's family. Palliative care can be delivered in a variety of settings (hospital, outpatient clinic, nursing home, or home).

Although they are not available in all rural communities and areas in Wisconsin, more and more health care institutions are developing palliative care programs. **In health care settings without a dedicated palliative care program, it is important to note that most palliative care is not provided by specialty level palliative care teams.** Instead, care is provided by the patient's primary care providers. **Therefore, it is important to talk with your doctors about your preferences for care at the end of life.**

## **THE RIGHT KIND OF CARE**

Typically, dying patients require a lot of care in order to preserve their **dignity** and **comfort**. Usually, common elements seen in medical hospitals—i.e., IVs, x-rays, ventilators, blood draws, blood pressure cuffs—are not needed to appropriately care for a dying person.



**Proper medical care for a dying patient includes:**

- A warm, safe environment that celebrates the person, his/her loved ones, and his/her culture.
- Access to medications to treat common symptoms such as pain, shortness of breath, confusion, and fevers.
- Common medical equipment such as hospital beds.
- **Most importantly: dying patients require considerable love and attention from their family, social network, and nursing support.**

This guide was created to accompany the 2011 statewide tour of **From the Start, Consider the Finish, presented by Milwaukee Public Theatre and Voices Theater.** The musical play was adapted by Rogers Keene from the award-winning book by Susan Dolan and Audrey Vizzard: **The End of Life Advisor: Personal, Legal and Medical Considerations for a Peaceful, Dignified Death,** Kaplan Publishing, December 2008.

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