

Update:

Final Choices

The End of Life Options



Dying in America

Dying in America today occurs far differently than it did even a generation ago. In the 1960s and 1970s, many people died of sudden causes, and diseases like cancer often took lives quickly. But with improvements in modern medicine, safety and technology, immediate and rapid causes of death have declined dramatically. At the same time, gradual causes of death have grown exponentially. Cancer, Alzheimer's, and a host of other conditions that slowly rob the body of its function and faculties leading to prolonged suffering are common today, and they have changed the way many of us die.

In 1920, 75% of Americans died at home. By the 1990s, 75% died in hospitals or other medical institutions such as nursing homes. Though most Americans say they want to die at home, many die in a hospital's Intensive Care Unit (ICU), often after dramatic medical interventions that may not have, in retrospect, prolonged their lives.

Traditional Western medicine's focus on preserving life, often utilizing advanced technology, can highlight the differing goals of health care providers and patients. Patients want quality lives, but many medical interventions merely prolong life rather than provide healing. Therefore patients must clearly communicate how they want to live and die. If you and your family don't discuss your care preferences with your doctors, they are obligated to do everything they can to prolong your life, whether you desire it or not.

Awareness of and adherence to advance directives (see back page sidebar) is critical for patients seeking to live their final days on their own terms. Advance directives clarify your choices about the type of care you want. Consider your options. You may want doctors to take extraordinary measures to prolong your life. You may not. Either way, it's your choice, and you should consider it carefully before you and your loved ones find yourselves in an urgent situation.

Extraordinary measures, invasive procedures, and ICU stays are dramatic and life-saving ... and expensive. But, these interventions do not necessarily result in longer lives or comfortable deaths. An alternative, hospice care, focuses on interventions that greatly support end of life care with emphases on patient wishes and comfort. This palliative care (see back page sidebar), with its focus on patient comfort and peace of mind, is desired by many who are dying.

Home, hospital or nursing home? Medical heroics or letting nature take its course? The decisions are yours to make. And by planning and making choices about your end of life care now, your family can be prepared to honor your wishes.

Resources

Numerous books, broadcasts and web resources can help you learn more:

- *Last Rights: Rescuing the End of Life from the Medical System* by Stephen P. Kiernan
- *On Death and Dying* by Elisabeth Kubler-Ross,
- *The Art of Dying: The Only Book for Persons Facing Their Own Death* by Patricia Weenolsen
- *Final Gifts: Understanding the Special Awareness, Needs, and Communications of the Dying* by Maggie Callanan
- *Dying Well: Peace and Possibilities at the End of Life* by Ira Byock, MD
- "Moyers on Dying," a four-part series that focuses on end-of-life care, <http://www.pbs.org>
- Five Wishes Advance Directives – legally valid in 40 states
- http://www.AARP.org/families/end_life
- <http://www.reclaimtheend.org>
- <http://www.americangeriatrics.org>

About My Health Care Manager

My Health Care Manager helps older adults and their families understand and navigate the health issues and complex decisions associated with aging. For more information, contact My Health Care Manager, 8520 Allison Pointe Blvd., Suite 230, Indianapolis, IN 46250, 317-598-8921 or 800-499-8020 or visit us on the Web at www.MyHealthCareManager.com.

Issues at the End of Life

Death is a normal, natural part of life. And while it's unavoidable, what happens before we die is often within our control. Knowing what we will eventually face gives us an opportunity to shape our final days. Involving your loved ones, making decisions early, and documenting your health care preferences can help you ensure that your final wishes are honored.

Update or create a will that clarifies who will manage the distribution of your assets and what goes to which of your heirs. You can even take the time to make your own funeral and burial plans. Then talk with your family about all of these arrangements. This is also a chance to pass on to your family things you want them to know. Tell tales of family history, write your memoirs, or leave letters to young relatives about your wishes and dreams for their futures.

Preparing for death brings an opportunity to decide what you want from your remaining days and your passing. Ask yourself how you want to live, who will take care of you, where you want to spend your last days, and what kind of care you do or don't want to receive.

Compassionate care. A good doctor-patient relationship is essential to quality end of life care. Your doctor should be attentive, responsive, and respectful of your wishes. In an ideal situation, your family and doctors will work together to maximize your quality of life.

Ask your doctor where your illness might lead and what decisions you will face. Knowing the path a disease might take can make the battle less frightening. Learn your treatment options and make choices in relative calm, before a health crisis. The person with your power of attorney for health care (see sidebar) can represent your preferences if you are not able.

Involve your loved ones in planning your care. You may need them to advocate on your behalf, so make sure they'll honor your choices.

Advance directives. Make a plan for what health care you want to receive and for how long. How aggressive do you want health care providers to be in trying to prolong your life? Do you want to receive CPR if your heart stops? A breathing tube or feeding tube if they become necessary to keep you alive? For you, dying with dignity might mean avoiding these extreme measures. You can create advance directives that make these choices clear.

Once you decide, share your advance directives with your family and your doctors. Have them added to your medical chart. Make sure your family communicates your wishes, especially if you do not want to be resuscitated (set out in a DNR - Do Not Resuscitate physician order) to all medical personnel. As your situation and decisions may change, you should review your advance directives annually to make any changes necessary.

Pain management. Freedom from pain is critical to quality of life and a peaceful passing. There is no reason to experience unwanted pain at the end of life when effective pain management can help you balance alertness with relief.

End of life care. You may reach a point when you stop seeking medical interventions. When you do, you deserve compassionate care, respect for your final wishes, effective pain management, and a peaceful passage. Palliative care, such as hospice, can help you and your family deal with death in a comfortable and caring way. Though it is physician-directed, it's less about treating disease and more about caring for patient needs, managing pain, and helping you take care of any last wishes.

Know the Terminology

Advance directives are legal documents instructing doctors how to care for you at the end of your life.

They can specify what measures you do – and *do not* – want taken to sustain your life. There are three primary types:

- **Do not resuscitate orders (DNRs)** typically request that no extraordinary life-saving measures – CPR, defibrillation, intubation – be used when your long-term prognosis is poor. This is a physician order, so it is important to make your wishes known to your physician during any hospitalizations.
- **Living wills** are written documents specifying the type of treatment you wish to receive, usually refusing measures that unnecessarily lengthen the dying process. For your living will to take effect, you must be in a permanent coma or otherwise unable to make your own care decisions.
- **Durable power of attorney (DPA)** for health care designates a specific person, usually a family member or friend, to make decisions about your care if you are unable. Your designee is kept informed of your condition and can meet with doctors to discuss treatment options.

Palliative care is intended to help people achieve the best quality of life in their final days. It includes a strong focus on effective pain management and on psychological and spiritual aspects of end of life care. The best-known palliative care is hospice.

Moving to hospice doesn't mean you've given up hope, just that you want a peaceful way to live and die. It eases the caretaking burden on your loved ones, with care delivered by a team of people, including your family, working together to ensure last days filled with compassion and dignity.

Final days. Consider where you want to spend your last days. Hospice can be provided either in your home or in another setting. A majority of people say they want to die at home, in a familiar place surrounded by family and friends. Make your wishes known to your family and caregivers.