

End of Life Care: A Guide for Patients and Caregivers

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Dying is the final portion of the life cycle for all of us. Providing humane care near the end of life is an essential part of medicine. People near the end of life deserve to be treated with dignity and compassion. Every effort must be made to ensure that a patient's last days are spent in as much comfort as possible and according to the patient's wishes.

Q . Will I have to go to the hospital or can I end my days at home?

A . Dying at home is usually possible, provided you have family and/or other caregivers to help you. Advanced planning and discussion of such issues while you are still healthy is always a good idea. Be sure your family and other caregivers know your wishes and are able and willing to implement them.

Q . Does pain and suffering have to be a part of dying?

A . Pain can almost always be controlled. Other suffering that may occur at the end of life include worries about financial concerns, guilt feelings, regret, unfinished family business, etc. These feelings can all be helped.

Q . If I cannot eat or drink by mouth, will I have to be fed by a needle or a feeding tube?

A . Most people at the end of life do not feel hunger or thirst. Artificial feeding does not help most dying persons-it can even make them feel worse. Good mouth care gives comfort and ice chips (which can be flavored) cool the mouth and provide hydration.

Q . I have heard about hospice. What is this?

A . Hospice is a program that cares for dying persons. Inpatient and home hospice services are generally short term to control pain and to provide other comfort. Hospice professionals are experienced in controlling pain and other symptoms, and can help when caregivers need a break.

Q . I don't want to be alone. Who can be with me when my family has to go to work?

A . A variety of community programs, including hospices, train volunteers to help as companions, visitors, drivers, etc. Programs in your community may also be operated or sponsored by churches, hospitals, and municipal agencies.

Q . Who will help me find volunteers, arrange for my care, help me get a hospital bed and other items I will need?

A . Your health insurance usually requires that your physician authorize equipment and treatment by professionals at home. Depending on your insurance coverage (e.g., Medicare), this may include visiting nurses and therapists and someone to help with your personal needs, such as eating and bathing. Since many older patients rely on Medicare for their health care insurance, it is a good idea for you and your caregiver to discuss which services Medicare covers. Many organizations that provide these services (nursing, therapy, etc.) also have social workers or other case managers who can help identify available resources and programs. Community service organizations and churches are often available to assist you.

Q . If I can't stay in the hospital or at home, where else can I live and get the care I need?

A . Depending on your medical condition and your finances, places such as nursing homes, assisted living facilities and group homes might meet your needs. Your doctor, a social worker or a case manager may be able to help you find the right place.

Q . How can I make sure that my doctor and my family know what care I want when I am no longer able to speak for myself?

A . The key is to plan early, in case you can't speak for yourself later, so you can participate actively in your care plan (This is a practical idea for all older adults, not just those nearing the end of life.). "Advance directive" is a general term that describes the type of legal documents that "speak" for you in the event you are too ill to speak for yourself in the future. These advance directives are the "living will," and the medical power of attorney.

- A living will describes your care decisions concerning medical treatment at the end of your life.
- A medical power of attorney (or health care proxy) allows you to appoint the person(s) you trust to make health decisions for you if you cannot, and clearly states your wishes for resuscitation, feeding tubes, antibiotics, transfers to hospitals, respirators, etc.

Advance directives are legally valid throughout the United States. The laws governing them vary from state to state, so sign advance directives that comply with your state's law. Also, advance directives can have different titles in different states. Forms approved for the state you live in are available from many different health care organizations and institutions, and can sometimes even be purchased at stationery stores. You do not need to pay anyone to help you complete these documents. Discuss your wishes with your doctor and the person(s) appointed to carry out your treatment wishes and be sure to provide them with copies of these documents. Your doctor and you may also wish to complete a special form that ensures your wishes are followed if a rescue squad is called to your home. Make copies of all such documents and be sure that you (and a caregiver) take a copy if you are hospitalized.



Q . Where do I go for more information?

A . More detailed information can be obtained through organizations such as:

- [The National Hospice Organization](#) (800-658-8898, 9AM-5PM EST)
- [National Association for Home Care](#) (202-547-7424)
- [Partnership for Caring](#) (800-989-9455)
- [Legal Services for the Elderly](#) (212-391-0120)
- [The Visiting Nurse Association of America](#) (800-426-2547)

Other good sources are local affiliates of organizations such as the American Cancer Society, the American Heart Association and the Alzheimer's Disease Association. Also, local agencies on aging and home health agencies are valuable sources of information.

- [The Care of Dying Patients](#)
 - [Measuring Quality of Care at the End of Life-A Statement of Principles](#)
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