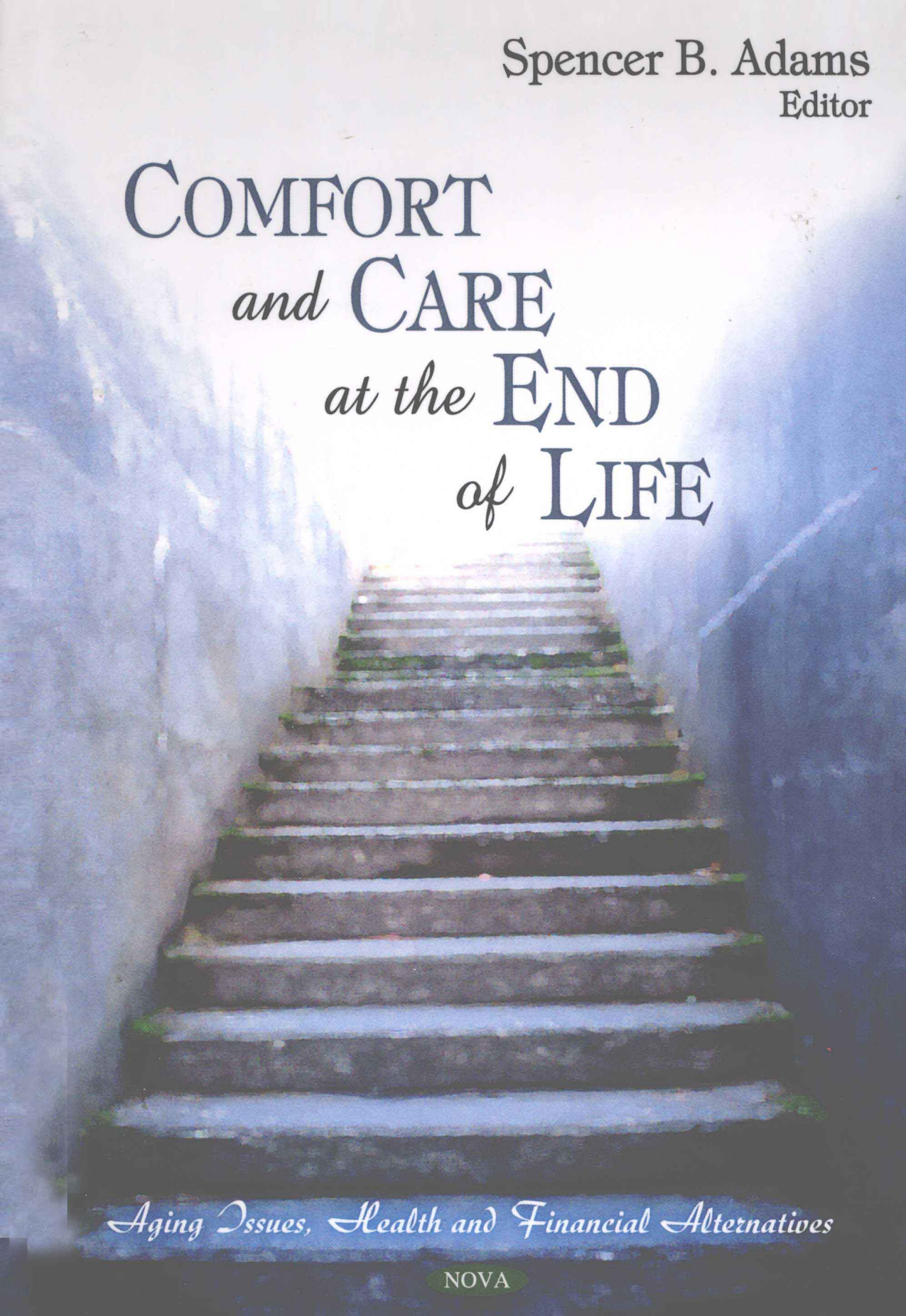
Spencer B. Adams
Editor

Comfort and Care at the End of Life



Aging Issues, Health and Financial Alternatives

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AGING ISSUES, HEALTH AND FINANCIAL ALTERNATIVES

COMFORT AND CARE AT THE END OF LIFE

SPENCER B. ADAMS
EDITOR

常州大学山书馆
藏书章

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PREFACE

For some elderly people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll. But for everyone, death is inevitable, and each loss is personally felt by those close to the one who has died. End-of-life care is the term used to describe the support and medical care given during the time surrounding death. An older person is often living, and dying, with one or more chronic illnesses and needs a lot of care for days, weeks, and sometimes even months. This book explores helping with comfort and care at the end-of-life and hopes to make the unfamiliar territory of death slightly more comfortable for everyone involved. Discussions on hospice, end-of-life services, costs, ethics, and quality of care are contained herein.

Chapter 1 - Hospice is a concept of care that involves health professionals and volunteers who provide medical, psychological, and spiritual support to terminally ill patients and their loved ones. Hospice stresses quality of life—peace, comfort, and dignity. A principal aim of hospice is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice services are available to persons who can no longer benefit from curative treatment; the typical hospice patient has a life expectancy of 6 months or less. Hospice programs provide services in various settings: the home, hospice centers, hospitals, or skilled nursing facilities. Patients' families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

Chapter 2 - At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually failing. For some older people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll. But for everyone, death is inevitable, and each loss is personally felt by those close to the one who has died.

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen just in the moments before breathing finally stops and a heart ceases to beat. An older person is often living, and dying, with one or more chronic illnesses and needs a lot of care for days, weeks, and sometimes even months.

End of Life: Helping With Comfort and Care hopes to make the unfamiliar territory of death slightly more comfortable for everyone involved. This publication is based on research, such as that supported by the National Institute on Aging, part of the National Institutes of Health. This research base is augmented with suggestions from practitioners with expertise in helping individuals and families through this difficult time. Throughout the booklet, the terms comfort care, supportive care, and palliative care are used to describe individualized care that can provide a dying person the best quality of life until the end. Most of the stories in this

booklet are fictitious, but they depict situations that reflect common experiences at the end of life.

When a doctor says something like, "I'm afraid the news is not good. There are no other treatments for us to try. I'm sorry," it may close the door to the possibility of a cure, but it does not end the need for medical support. Nor does it end the involvement of family and friends. There are many places and a variety of ways to provide care for an older person who is dying. Such care often involves a team. If you are reading this, then you might be part of such a team.

Helping With Comfort and Care provides an overview of issues commonly facing people caring for someone nearing the end of life. It can help you to work with health care providers to complement their medical and caregiving efforts. The booklet does not replace the personal and specific advice of the doctor, but it can help you make sense of what is happening and give you a framework for making care decisions.

Chapter 3 - End-of-life care can be broadly defined as health care provided to persons who are very ill, have a prognosis that is likely to worsen, and most likely will die in the near term from their illness. Endof-life care may be in the form of acute care provided in the days or months prior to death or palliative care, which focuses on relieving the patient's suffering and reducing the severity of disease symptoms as well as improving quality of life. Hospice care is a form of palliative care that delivers comfort care to those who forgo curative treatment and have a life expectancy that can be measured in months. Achieving a health care system where the provision of end-of-life care services are sensitive to and accommodate the needs of all those involved requires attention to a range of ethical and policy issues, including personal choice, cost, and quality of care.

Over the past century, several demographic and historical changes have affected the experience of death and dying in the United States. The development of new technologies, and the associated prospect of longer, more protracted deaths, has focused some policy discussions on the topic of patients' preferences. Federal law generally defers to state law concerning health-care decision making. Given the complexities in decision making surrounding medical interventions that have life-extending potential, states have passed laws to address end-of-life care issues, such as advance directives. However, there is considerable variation among state laws.

Costs of care at the end of life may be paid by Medicare or Medicaid, private insurance, or out-of- pocket. According to CMS, about one-fourth of total Medicare spending is for the last year of life. This share has remained generally constant for the past 20 years. The majority of Medicare endof-life costs are from inpatient hospital expenditures. Researchers have also found that there is wide geographic variation in end-of-life Medicare costs. This geographic variation may reflect differences in practice patterns of physicians and is not necessarily due to differences in prevalence of disease among chronically ill patients.

End-of-life care presents numerous challenges and opportunities for quality measurement, assessment, and improvement. Assessments of quality end-of-life care are often based on family and patient satisfaction. Factors associated with perceptions of higher quality care include expressions of patients' wishes, discussions of families' spiritual needs, documentation of a living will, and family presence at the time of death. A number of initiatives are currently underway to improve the quality of care individuals receive at the end of life, and specifically the quality of palliative and hospice care.

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As the nation prepares for an aging population and likely increase in the need for high quality end-of-life care services among the elderly, Congress may face a decision whether to expand the role of the federal government in providing support to individuals and families to assist with endof-life care. This chapter provides information on various aspects of end-of-life care. The report is divided into six sections that address (1) demographic and historical changes affecting death and dying in the United States; (2) the definitions of end-of-life, palliative, and hospice care; (3) costs associated with end-of-life care; (4) end-of-life care laws and ethics; (5) quality of care at the end of life; and (6) policy issues that would modify or expand the federal government's role in addressing end-of-life care.

Chapter 4 - Approximately 28 percent of all Medicare spending in 1999 was used to provide care for beneficiaries in the last year of their lives. The Medicare hospice benefit is specifically designed for end-of-life care but is an elected benefit for individuals who have a terminal diagnosis with a prognosis of 6 months or less if the disease runs its normal course. GAO was asked to identify examples of programs that provide key components of end-of-life care. Specifically, GAO (1) identified key components of end-of-life care, (2) identified and described how certain programs incorporate key components of end-of-life care, and (3) described the challenges program providers have identified to delivering the key components of end-of-life care. To identify the key components of end-of-life care, GAO relied on studies by the Institute of Medicine (IOM) and the Agency for Healthcare Research and Quality (AHRQ). To identify and describe programs that implement these key components and describe the challenges providers of these programs face, GAO conducted site visits to four states, Arizona, Florida, Oregon, and Wisconsin, that, in addition to other criteria, demonstrated a high use of end-of-life services. We interviewed officials of federal, state, and private programs in these four states that provide care to individuals nearing the end of life.

Chapter 5 - This is an edited, excerpted and augmented edition of a National Institutes of Health End-of-Life Fact Sheet.

Chapter 6 - This chapter is edited and excerpted testimony by Patricia A. Bomba before the Special Committee on Aging on September 24, 2008.

Chapter 7 - This chapter is edited and excerpted testimony by Joan Curran before the Special Committee on Aging on September 24, 2008.

Chapter 8 - This chapter is edited and excerpted testimony by W.A. Drew Edmondson before the Special Committee on Aging on September 24, 2008.

Chapter 9 - This chapter is edited and excerpted testimony by Senator Herb Kohl before the Special Committee on Aging on September 24, 2008.

Chapter 10 - This chapter is edited and excerpted testimony by Diane E. Meier before the Special Committee on Aging on September 24, 2008.

Chapter 11 - This chapter is edited and excerpted testimony by Joseph D. O'Connor before the Special Committee on Aging on September 24, 2008.

Chapter 12 - This chapter is edited and excerpted testimony by Senator Sheldon Whitehouse before the Special Committee on Aging on September 24, 2008.

Chapter 13 - This chapter is edited and excerpted testimony by Joan M. Teno before the Special Committee on Aging on September 24, 2008.

Chapter 14 – Hospice is a program of care and support that you may want to consider if you or someone you care for is terminally ill. Here are some important facts about hospice:

- 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 or 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 and related condition(s).
- Hospice isn't only for people with cancer.
- Hospice doesn't shorten or prolong life.
- Hospice focuses on comfort, not on curing an illness.

Chapter 15 - Hospice care provides an interdisciplinary approach to services for Medicare beneficiaries with a terminal illness. This care specializes in the relief of the pain and symptoms associated with a terminal illness and in the provision of supportive and counseling services to patients and their families during the final stages of a patient's illness and death. The benefit covers a broad range of services, including prescription drugs for pain control and symptom management, skilled nursing care, physician services, home health aide services, homemaker services, patient counseling, and family bereavement counseling. Services are provided primarily in the patient's home, but may also be provided in institutional settings, such as nursing homes. Hospice care is provided in lieu of most other Medicare services related to the curative treatment of the terminal illness.

For a person to be considered terminally ill and eligible for Medicare's hospice benefit, the beneficiary's attending physician and the medical director of the hospice (or physician member of the hospice team) must certify that the individual has a life expectancy of six months or less. Beneficiaries electing hospice are covered for two 90-day periods, followed by an unlimited number of 60-day periods.

Medicare payments to hospices in 2007 totaled $10.1 billion, having more than tripled since 2000. Medicare spending for hospice is expected to continue growing and to more than double by 2018, reaching a projected $21 billion and outpacing the projected growth rates for Medicare payments in hospitals, skilled nursing facilities, physician services, and home health care. Growth in spending to date has been driven, in part, by increased utilization of hospice as well as spending per hospice user. For example, spending per user grew between 2004 and 2005 by 8%. Growth in spending per user may be in part a result of increasing lengths of stay among certain hospice providers.

The number of hospices participating in Medicare also grew by 33.4% during the four-year period from 2003 to 2007. As of 2007, for-profit hospices constituted the majority of these hospices, and since 2000, made up over 90% of hospices participating in Medicare.

Medicare pays hospices using a prospective payment system containing four categories of daily rates, which are predetermined, fixed amounts intended to pay for the costs of care for a hospice beneficiary, on average. These amounts are adjusted annually by the hospice market basket. Hospice payments are also adjusted for geographical differences. Total payments to hospices may not exceed an aggregate per beneficiary cap amount.

Some analysts have expressed concerns about Medicare margins earned by certain types of hospice providers, the growing number of hospices exceeding the aggregate per beneficiary cap, increasing lengths of stay, and the three-year phase out of the budget neutrality factor authorized under regulation in August of 2008.

Chapter 16 - The circumstances giving rise to Gonzales v. Oregon involved the emotionally charged political and moral debate over physician-assisted suicide and end-of-life

decision making. However, the matter in controversy did not require the U.S. Supreme Court to weigh in on the merits of physician-assisted suicide or the constitutionality of the Oregon statute that sanctioned and regulated such practice. Rather, it presented the Court with a question concerning the scope of authority granted by a federal statute: Whether the Controlled Substances Act (CSA) and its implementing regulations authorized the Attorney General to prohibit the distribution of federally controlled substances for the purpose of facilitating an individual's suicide, regardless of the state of Oregon's law that permits such distribution. Writing the opinion of the Court, which was joined by five other justices, Associate Justice Anthony M. Kennedy relied on a statutory interpretation of the CSA to determine that the Attorney General had exceeded his authority under the CSA when he issued a rule declaring the use of controlled substances for physician assisted suicide to be a violation of the CSA. As a consequence of this decision, a physician acting pursuant to the Oregon Death with Dignity Act to hasten the death of a terminally ill patient does not commit a per se violation of the CSA - thus he or she cannot be subjected to federal criminal prosecution on this particular ground, nor can the physician's authority to prescribe controlled substances be revoked on this basis.

Chapter 17 - As we age and live longer, financial, legal, health care and long term care issues affect families, not just individuals. The Eldercare Locator produced this guide to help families "face the facts" about these important topics. The overview below addresses some key areas of concern, suggested questions to ask, and ways in which families might initiate conversations about these often difficult to discuss topics with their aging parents.

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Chapter 1

HOSPICE

National Cancer Institute

Hospice is a concept of care that involves health professionals and volunteers who provide medical, psychological, and spiritual support to terminally ill patients and their loved ones. Hospice stresses quality of life—peace, comfort, and dignity. A principal aim of hospice is to control pain and other symptoms so the patient can remain as alert and comfortable as possible. Hospice services are available to persons who can no longer benefit from curative treatment; the typical hospice patient has a life expectancy of 6 months or less. Hospice programs provide services in various settings: the home, hospice centers, hospitals, or skilled nursing facilities. Patients' families are also an important focus of hospice care, and services are designed to provide them with the assistance and support they need.

The following resources may offer assistance for people seeking hospice care and information:

- The **National Hospice and Palliative Care Organization** (NHPCO) is a membership organization representing programs and professionals that provide hospice and palliative care in the United States. NHPCO's mission is to lead and mobilize social change for improved care at the end of life. NHPCO offers publications, information about how to find a hospice, and information about the financial aspects of hospice. Some Spanish- language publications are available, and staff are able to answer calls in Spanish.

Address:	Suite 625 1700 Diagonal Road Alexandria, VA 22314
Telephone:	703–837–1500 1–800–658–8898 (helpline)
E-mail:	nhpco_info@nhpco.org
Web site:	http://www.nhpco.org/templates/1/homepage.cfm

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- The **Hospice Association of America** (HAA) is an advocate for hospice organizations. It serves hospices that are freestanding and community-based, as well as those affiliated with home care agencies and hospitals. HAA also distributes a number of publications about hospice to consumers. Publications can be viewed by accessing the organization's Web site. Topics include information about the history of hospice, the benefits of choosing a hospice program, hospice-related statistics, and locations of hospice organizations.

Address: 228 Seventh Street, SE.
Washington, DC 20003
Telephone: 202–546–4759
Web site: http://www.nahc.org/HAA/home.html

- The **Hospice Education Institute** serves a wide range of individuals and organizations interested in improving and expanding hospice and palliative care throughout the United States and around the world. The Institute works to inform, educate, and support people seeking or providing care for the dying and the bereaved. HOSPICELINK, a service of the Institute, maintains a computerized database and up-to-date directory of all hospice and palliative care programs in the United States. HOSPICELINK helps patients and their families find hospice and palliative care programs, and provides general information about the principles and practices of good hospice and palliative care.

Address: 3 Unity Square
Post Office Box 98
Machiasport, ME 04655–0098
Telephone: 207–255–8800
1–800–331–1620
E-mail: info@hospiceworld.org
Web site: http://www.hospiceworld.org

- **Hospice Net** is an organization that works exclusively through the Internet. This organization's Web site provides hospice-related information for patients, children, and caregivers. It contains articles regarding end-of-life issues and is dedicated to providing information and support to patients facing life-threatening illnesses and to their families and friends.

Address: Suite 51
401 Bowling Avenue
Nashville, TN 37205–5124
E-mail: info@hospicenet.org
Web site: http://www.hospicenet.org

- The **American Cancer Society** (ACS) provides free fact sheets and publications about hospice. The address of a local ACS chapter can be obtained by calling the chapter's toll-free telephone number.

Telephone: 1–800–ACS–2345 (1–800–227–2345)
Web site: http://www.cancer

For many people, some hospice expenses are paid by health insurance plans (either group policies offered by employers or individual policies). Information about the types of medical costs covered by a particular policy is available from an employee's personnel office, a hospital or hospice social worker, or an insurance company. Medical costs that are not covered by insurance are sometimes tax deductible.

Medicare, a health insurance program for the elderly or disabled that is administered by the Centers for Medicare & Medicaid Services (CMS) of the Federal Government, provides payment for hospice care. When a patient receives services from a Medicare-certified hospice, Medicare insurance provides substantial coverage, even for some services that would not be covered outside of a hospice program. To find a Medicare-certified hospice program, people can ask their doctor, a state hospice organization, or the state health department. The telephone number for state hospice organizations and health departments can be found in the state government section of a local telephone directory. The Medicare hotline can answer general questions about Medicare benefits and coverage, and can refer people to their regional home health intermediary for information about Medicare-certified hospice programs. The toll-free telephone number is 1–800–MEDICARE (1–800–633–4227); deaf and hard of hearing callers with TTY equipment can call 1–877–486–2048. The booklet *Medicare Hospice Benefits* is the official publication for Medicare hospice benefits. This booklet, which outlines the type of hospice care that is covered under Medicare and provides detailed information about hospice coverage, is available at http://www.medicare.gov/ Publications/ Pubs/pdf/02154.pdf on the Internet.

Medicaid, a Federal program that is part of CMS and is administered by each state, is designed for patients who need financial assistance for medical expenses. Information about coverage is available from local state welfare offices, state public health departments, state social services agencies, or the state Medicaid office. Information about specific state locations may also be found at http://cms.hhs.gov/medicaid on the Internet.

In addition, local civic, charitable, or religious organizations may be able to help patients and their families with hospice expenses.

Related Resources

Publications (available at http://www.cancer

- National Cancer Institute Fact Sheet 8.1, *National Organizations That Offer Services to People With Cancer and Their Families*
- National Cancer Institute Fact Sheet 8.12, *Advance Directives*
- National Cancer Institute Fact Sheet 8.15, End-of-Life Care: *Questions and Answers*
- *Coping with Advanced Cancer*
- *When Someone You Love Has Advanced Cancer: Support for Caregivers*

National Cancer Institute (NCI) Resources

Cancer Information Service (toll-free)

Telephone: 1–800–4–CANCER (1–800–422–6237)
TTY: 1–800–332–8615

Online

NCI's Web site: http://www.cancer
LiveHelp, NCI's live online assistance:
https://cissecure.nci.nih.gov/livehelp/welcome.asp

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Chapter 2

END OF LIFE: HELPING WITH COMFORT AND CARE

National Institute on Aging and National Institutes of Health

Empty-handed I entered the world, Barefoot I leave it. My coming, my going Two simple happenings That got entangled.

— Kozan Ichikyo (d. 1360)

INTRODUCTION

At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually failing. For some older people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll. But for everyone, death is inevitable, and each loss is personally felt by those close to the one who has died.

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When a doctor says something like, "I'm afraid the news is not good. There are no other treatments for us to try. I'm sorry," it may close the door to the possibility of a cure, but it does not end the need for medical support. Nor does it end the involvement of family and friends. There are many places and a variety of ways to provide care for an older person who

is dying. Such care often involves a team. If you are reading this, then you might be part of such a team.

Helping With Comfort and Care provides an overview of issues commonly facing people caring for someone nearing the end of life. It can help you to work with health care providers to complement their medical and caregiving efforts. The booklet does not replace the personal and specific advice of the doctor, but it can help you make sense of what is happening and give you a framework for making care decisions.

Providing Comfort: At the End of Life

Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying. The goal is to prevent or relieve suffering as much as possible while respecting the dying person's wishes.

You are probably reading this because someone close to you is dying. Is it a parent or grandparent, your husband or wife, a favorite aunt or uncle, your best friend? You wonder what will happen. You want to know how to give comfort, what to say, what to do. At the same time, you're possibly unsure about what is needed, worried about doing the wrong thing, or afraid of being there—or not being there—at the moment of death.

You might be giving day-to-day care to the dying person, chosen to make health care decisions, or a close family member or friend who wants to help. You would like to know how to make dying easier—how to help ensure a "good death," with treatment consistent with the dying person's wishes.

A "good death" might mean something different to you than to someone else. Your sister might want to know when death is near so she can have a few last words with the people she loves and take care of personal matters. Your husband might want to die quickly and not linger. Perhaps your mother has said she would like to be at home when she dies, while your father wants to be in a hospital where he can receive treatment for his illness until the very end. Some people want to be surrounded by family and friends; others want to be alone. Of course, often one doesn't get to choose, but having your end-of-life wishes followed, whatever they are, and being treated with respect while dying are common hopes.

Generally speaking, people who are dying need care in four areas—physical comfort, mental and emotional needs, spiritual issues, and practical tasks. In this chapter you will find a number of ways you can be of help to someone who is dying. Always remember to check with the health care team to make sure these suggestions are appropriate.

Comfort needs near the end of life

- Physical Comfort
- Mental and Emotional Needs
- Spiritual Issues
- Practical Tasks

Physical Comfort

There are ways to make a person who is dying more comfortable. Discomfort can come from a variety of problems. For each there are things you or a health care provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

- Pain
- Breathing problems
- Skin irritation
- Digestive problems
- Temperature sensitivity
- Fatigue

Pain. Watching someone you love die is hard enough, but thinking that person is also in pain makes it worse. Not everyone who is dying experiences pain, but there are things you can do to help someone who does. Experts believe that care for someone who is dying should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse. Don't be afraid of giving as much pain medicine as is prescribed by the doctor. Pain is easier to prevent than to relieve, and overwhelming pain is hard to manage. Try to make sure that the level of pain does not "get ahead" of pain-relieving medicines. If the pain is not controlled, ask the doctor or nurse to arrange for consultation with a pain management specialist.

Struggling with severe pain can be draining. It can make it hard for families to be together in a meaningful way. Pain can affect mood— being in pain can make someone seem angry or short-tempered. Although understandable, irritability resulting from pain might make it hard to talk, hard to share thoughts and feelings.

WHAT ABOUT MORPHINE?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling ofshortness of breath. You might have heard that giving morphine leads to a quicker death. Is that true? Most experts think thisis unlikely, especially if increasing the dose is done carefully. Successfully reducing pain and/or concerns about breathing can provide needed comfort to someone who is close to dying.

Breathing problems. Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this *dyspnea (disp-NEE-uh).* Worrying about the next breath can make it hard for important conversations or connections. Try raising the head of the bed, opening a window, using a vaporizer, or having a fan circulating air in the room. Sometimes, the doctor suggests extra oxygen, given directly through the nose, to help with this problem.

People very near death might have noisy breathing called a *death rattle.* This is caused by fluids collecting in the throat or by the throat muscles relaxing. It might help to try turning the person to rest on one side. There is also medicine that can be prescribed to help clear this up. But not all noisy breathing is a death rattle. And, it may help to know that this noisy breathing is usually not upsetting to the person dying, even if it is to family and friends.

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