

END-OF-LIFE

Care



Chapter 4

Palliative Care

Chapter 4: Palliative Care

A Vision for Better Care at the End of Life

Palliative care, according to the World Health Organization (WHO), is the active total care of a patient whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual concerns are the primary goals of care. Many aspects of palliative care are applicable early in the course of a terminal illness.

The WHO states that palliative care:

- Aims to achieve the best possible quality of life for patients and their families
- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help the family cope during the patient's illness and in subsequent bereavement.

Last Acts Five Principles of Palliative Care

The *Last Acts* organization, a coalition of 400 organizations representing health care providers and patients nationwide, believes that everyone can make a difference in the care given to dying people and their families.

Five Principles of Palliative Care have been developed by the *Last Acts* Task Force on Palliative Care and the Family. These principles may seem just common sense. However, when taken together, they provide a new and more complete way to look at end-of-life care.

The Physician's Role in Palliative Care

Physicians have an ethical obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care.



Five Principles of Palliative Care

- Palliative care respects the goals, likes and choices of the dying person
- Palliative care looks after the medical, emotional, social and spiritual needs of the dying person
- Palliative care supports the needs of the family members
- Palliative care helps gain access to needed health care providers and appropriate care settings
- Palliative care builds ways to provide excellent care at the end of life.

The American Medical Association's Code of Medical Ethics states patients must not be abandoned once it is determined cure is impossible. Patients nearing the end of life must receive good communication, emotional support, comfort care, adequate pain control and respect for their wishes, goals and values.

Near the end of life, physicians need to accompany and guide their patients through this critical transition. This includes:

- Providing the best estimates of prognoses
- Identifying situations where palliative care reasonably might supersede the desire for aggressive therapy
- Giving permission to patients to forego further aggressive treatment.

Making the Transition from Curative to Palliative Care

Identifying when to stop curative care and focus solely on palliative care is perhaps the most difficult aspect of treating a terminally ill patient.

Two fundamental facts ensure that the transition to death will remain difficult for many patients: the widespread and deeply held desire to avoid death, and medicine's inability to precisely predict when death will occur.

Patients facing a terminal illness have different responses. Some may be willing to pay a high price in quality of life to live a few days or a few weeks longer.

Others will not. Many other factors, such as cultural values or family dynamics, may affect how a patient decides to make the transition to dying. Patients with severe cognitive impairment may present additional and unique challenges.

Americans for Better Care of the Dying (ABCD) suggests that physicians ask themselves as they see patients, "Would I be surprised if this patient died this year?" For those "sick enough to die," learn about the patient's concerns. These concerns often can be addressed by a combination of symptom relief, family support, continuity of care, advance planning and spiritual care.

The ABCD suggests a physician next might ask, "What do you hope for as you live with this condition? What would be left undone in your life? How are things going for you and your family?" Use the answers to help develop a care plan that reflects the patient's concerns.

The transition to dying is rarely simple or conclusive. A patient may refuse definitive treatment such as surgery or chemotherapy, but as the illness progresses, decisions need to be made about accepting other treatments such as transfusions, antibiotics, feeding tubes and attempted cardiopulmonary resuscitation.

For more information about palliative care, see the web sites listed at the end of this chapter. Withholding or withdrawing treatment is discussed in the next chapter, and hospice care is the focus of Chapter 6.

Physician Requirements of the Michigan Dignified Death Act

The Michigan Dignified Death Act (1996 Public Act 594) is an informed consent law intended to increase terminally ill patients' awareness of their rights to decide whether to receive, continue, discontinue or refuse medical treatment.

The act requires a physician who recommends medical treatment for a person with a terminal illness to inform the patient, the patient's surrogate decision-maker or patient advocate—both orally and in writing—about the recommended treatment and alternatives. This includes giving information about the advantages, disadvantages and risks of the recommended treatment and each alternative, and about the specific procedures involved.

It also requires a physician to provide information about palliative care, including hospice and pain management. The law provides certain immunities for compliance and offers certain liability protections when prescribing controlled substances.

Palliative Care Resources

Web Sites

www.aahpm.org—American Academy of Hospice and Palliative Medicine—provides information on the advancement of hospice and palliative medicine, its practice, research and education. Interactive site with tools to assist physicians.

www.abcd-caring.com—Americans for Better Care of the Dying (ABCD)—is dedicated to social, professional and policy reform aimed at improving the care system for patients with serious illness and for their families.

www.americangeriatrics.org—The American Geriatrics Society—is a professional organization of health care providers dedicated to improving and effecting change for the health and well-being of older adults.

www.aap.org/policy/re0007—American Academy of Pediatrics—provides a statement, “Palliative Care for Children,” which presents an integrated model for providing palliative care for children living with a life-threatening or terminal condition.

www.capcmssm.org—Center to Advance Palliative Care (CAPC)—provides technical assistance needed to establish palliative care programs as well as opportunities to network with colleagues in the palliative care community.

www.careofdying.org—Supportive Care of the Dying—develops and tests innovative projects with individuals and organizations working to improve delivery of care to those facing the end of life. Videos and facilitator guides are available to help improve physician communication with patients and families.

www.dyingwell.org—Dying Well—lists resources and referrals to empower persons with life-threatening illnesses and their families to live as fully as possible during the dying process.

www.epec.net—The Education for Physicians on End-of-life Care (EPEC) Project—is designed to educate physicians around the country on the essential clinical competencies in end-of-life care.

www.growthhouse.org—Growth House: Guide to Death, Dying, Grief, Bereavement and End-of-Life Resources—offers search engine access to the Internet’s

most comprehensive collection of reviewed resources for end-of-life care.

www.lastacts.org—Last Acts—a call-to-action campaign dedicated to improving end-of-life care through sharing ideas and solutions by professional caregivers, institutions and individuals.

www.midbio.org—Community-State Partnerships to Improve End-of-Life Care, Midwest Bioethics Center—supports statewide coalitions to improve care of the dying, including the Michigan Partnership for the Advancement of End-of-Life Care.

www.mihospice.org—Michigan Hospice and Palliative Care Organization—includes a list of and links to all hospice organizations in Michigan.

www.msms.org/endoflifecare—Michigan State Medical Society—includes a list of EPEC-trained physicians and board certified palliative medicine specialists.

www.nhpco.org—National Hospice and Palliative Care Organization—is the industry’s largest association and leading resource for professionals and volunteers committed to providing services to patients and their families during the end of life.

www.partnershipforcaring.org—Partnership for Caring: America’s Voices for the Dying—a national non-profit organization devoted to raising consumer expectations and demand for excellent end-of-life care. Offers resources for talking about end-of-life choices, the process of health care agency and state-specific advance directives.

Books

- Approaching death: Improving care at the end of life. Cassel C., Field M. National Academy Press: 1997.
- Oxford textbook of palliative medicine, 2nd ed. Doyle D., Hanks GWC, MacDonald N. eds. Oxford, England: Oxford University Press: 1998.
- Primer of palliative care. Storey P. Academy of Hospice and Palliative Care Physicians: 1994.

- Your life, your choices, planning for future medical decisions: How to prepare a personalized living will. Pearlman R., Starks H., Cain K., Cole W., Rosengren D., Patrick D. Seattle, WA: Patient Decision Support: 1992.

Articles

- “Caring to the end: Policy suggestions and ethics education for hospice and home health care agencies.” Drane JF. Erie, PA: Lake Area Health Education Center: 1997.
- “Decisions near end of life.” Council on Ethical and Judicial Affairs. American Medical Association. *JAMA*. 1992;267:2229-2233.

- “Decisions to forgo life-sustaining treatment for incompetent patients.” In: *Council on Ethical and Judicial Affairs Reports on End-of-life Care*. Council on Ethical and Judicial Affairs, Chicago, IL: American Medical Association: 1998: 30-40.
- “Do-not-resuscitate orders.” In: *Council on Ethical and Judicial Affairs Reports on End-of-life Care*. Council on Ethical and Judicial Affairs. Chicago, IL: American Medical Association: 1998:1.
- “The ethical question: Death and dying.” (videotape/study guide). Orentlicher D. Chicago, IL: American Medical Association: 1996. The Ethical Questions Video/Study Guide Series.

Quotable

“The transition from curative to palliative care tends to be a cultural issue. There is reluctance on the part of the family, patient and medical system to face the fact that a person’s disease may be incurable. It’s easier to try another round of chemo or other therapies. Often patients still aren’t ready—even when their physician suggests hospice as the plan of care. Physicians can ease the transition by introducing the issue of comfort or palliative care early on and in conjunction with the curative treatment plan. By doing so, it will be easier to go back to the issue of hospice care six months or one year later if the disease continues to progress and is not curable.”

— Tom George, MD
Michigan State Representative
61st District, Kalamazoo, and
Medical Director
Hospice of Greater Kalamazoo

“Families are often concerned about how long their loved one has to live. I tell them there are no pat answers. No one can completely predict these things. I have seen some patients live for months who should have died rapidly based on the extent of their disease, and others die quickly and unexpectedly. The key thing we can do at hospice is ensure that their final days are comfortable.”

— Fred Isaacs, MD
Former Medical Director
Hospice of Lansing

End-of-Life Care: Finding Personal Comfort

Seeking Comfort in Relationships and Activities

People who are approaching the end of life may have personal matters or relationships that are not settled. An unsettled situation can prevent you from being in a comfortable frame of mind. These situations may not be apparent to your physician, family or friends unless questions are directly asked. Some questions to consider and then discuss with others include:

- Is there something you would like to do before you get too sick?
- Many people have old differences they would like to settle before they die. Is there anyone you want to be able to see or talk to before you die?
- Many people have places or people they would like to visit. Do you?
- Some people have a piece of work they would like to finish. Do you?
- In what ways has this illness affected you emotionally?
- Are you doing things you enjoy? What would you like to do today? Tomorrow?
- How has your mood been lately?
- How have you been coping with all of this?
- How have you handled stress in your life?
- Are you concerned about being a burden to others?
- Do you feel you have control in your life now?

When Time May Be Short

Some things to think about doing when time may be short include:

- Spend time with people who are important to you.
- Create a legacy for those who care about you. Letters, a tape recording or a video can be a special gift for your children and grandchildren.
- Call or ask an old friend to visit and tell your story to those who live on.
- Accept some compliments and gratitude.
- Forgive yourself and seek to make things right within your own faith.
- Say "I love you," "I'm sorry," "Forgive me," and "I forgive you."
- Right old wrongs.
- Take a last trip or two.
- Make time for spiritual issues and struggles.
- Say good-bye.
- Eventually, be at peace with the end to come and the uncertainty of when you will die.
- Make plans to ensure that your care and treatment will be as close as possible to what you want.

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