

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.



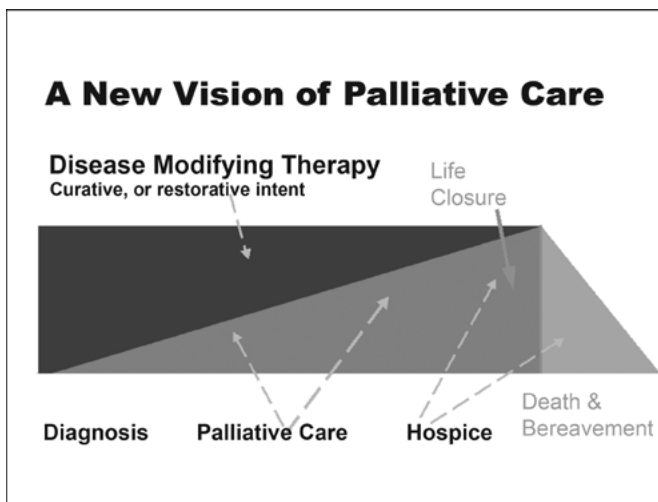
Five Principles of Palliative Care

- ♦ 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

Palliation of symptoms is a primary focus of care for terminally ill patients. But that does not mean the tools of palliative care should be withheld when a cure is still possible. Curative and palliative care can go hand in hand. Relieving pain and other difficult symptoms is a worthwhile goal at any stage; and doing so may also help the body respond more effectively to curative treatments.

Avoiding an either/or approach to palliative and curative care can also make decision-making easier when

the time comes to accept that cure is no longer the goal. Comfort care is less likely to be associated with abandonment or giving up hope when it has been part of the earlier treatment plan.

But making the decision to end curative treatments will still be difficult in many cases. Physicians, patients and families naturally resist accepting the imminence of death, and medicine's inability to predict precisely when death will occur may add an element of confusion.

Physicians can follow a suggestion from Americans for Better Care of the Dying (ABCD) and ask themselves, "Would I be surprised if this patient died this year?" When death seems a real possibility, it is important to make sure that the goals of care are built around the wishes and concerns of the patient.

ABCD further recommends that physicians ask the patient, "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?" The answers will also guide the development of a plan of care. The patient's concerns can usually be addressed by a combination of symptom relief, family support, continuity of care, advance planning and spiritual care, provided by the physician and other members of the care team.

Talking about the patient's goals, wishes and concerns will also help clarify their attitudes toward the use of potentially life-prolonging measures such as transfusions, antibiotics, feeding tubes and cardiopulmonary resuscitation. Some may be willing to pay a high price in quality of life in order to live a few additional days or weeks; others may not.

Other factors such as cultural norms or family dynamics may also affect a patient's decisions about ceasing curative or life-prolonging treatments. And patients with severe cognitive impairment may present additional and unique challenges. But, in fact, the transitions and decisions will follow an individual course for every patient according to the particulars of his or her life, which makes the physician's ability and willingness to listen all the more important.

For more information about palliative care, visit the websites 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 the awareness of a patient with a reduced life expectancy due to advanced illness 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 reduced life expectancy due to advanced 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

Websites

- ♦ **www.abcd-caring.org**—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.capc.org**—Center to Advance Palliative Care (CAPC) provides health care professionals with the tools, training and technical assistance necessary to start and sustain successful palliative care programs in hospitals and other health care settings.
- ♦ **www.dyingwell.org**—Dying Well website 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.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.

Books

- ♦ Eduardo Bruera, Charles F. Von Gunten, Irene J. Higginson, Carla Ripamonti. *Textbook of Palliative Medicine*. ©2009.
- ♦ Geoffrey Hanks, Russell K. Portenoy, Marie Fallon et al. *Oxford Textbook of Palliative Medicine*. 2010 Fourth Edition.
- ♦ Quill, T.; Holloway, R.; et al. *Primer of Palliative Care*. *American Academy of Hospice and Palliative Medicine*. Glenview IL, 2007.
- ♦ Morrison, RS.; Meier, DE. *Palliative Care*. *N Engl J Med* 350:2582, June 17, 2004.
- ♦ Joan M. Teno; Stephen R. Connor. *Referring a Patient and Family to High-Quality Palliative Care at the Close of Life: "We Met a New Personality...With This Level of Compassion and Empathy"* *JAMA*, February 11, 2009; 301: 651 - 659.
- ♦ T. Declan Walsh, Kathleen M. Foley, et al. *Palliative Medicine*. ©2008.

FOR MY PATIENTS

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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