

PALLIATIVE AND
HOSPICE CARE:

Caring Even When We Cannot Cure

The Catholic Health Association has developed this guide in collaboration with physicians, nurses, theologians and ethicists within Catholic health care and the Supportive Care Coalition, a national coalition of Catholic health ministries that advances excellence in palliative care. This guide is based on frequently asked questions to help you think about care during serious illness, including end-of-life decisions. Although the guide reflects the perspective of the Catholic tradition, the information can be helpful to people from any religious tradition. It is part of a series of publications from CHA to assist patients, families, physicians, nurses and care givers with decisions about serious illness and end-of-life care.

PALLIATIVE AND HOSPICE CARE

Caring Even When We Cannot Cure

Patients who are dealing with serious illness often experience pain, stress and discomfort, either because of the illness itself or the medical treatment they receive. They may be in pain or experience fatigue, shortness of breath, loss of appetite, nausea or have trouble sleeping. They may feel anxious, depressed or suffer from emotional or spiritual distress.

Palliative care helps patients with serious illness live as well as possible during their illness, and provides compassionate care to relieve the range of physical and emotional symptoms that often accompany serious illness or the side effects of treatment.

Although palliative medicine is a newly-named specialty in medicine, the idea behind it is far from new. Palliative care focuses on attending to the needs of the whole person — physically, psychologically, emotionally, socially, and spiritually. An interdisciplinary palliative care team — usually made up of doctors, nurses, social workers, chaplains, physical and occupational therapists, other professional care givers, and volunteers — works together to help patients deal with the physical and emotional effects of their illness.



With its emphasis on compassionate care and treatment, palliative care is a hallmark of Catholic health care, and is fully consistent with the Catholic moral tradition.

Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and the God of all consolation. He comforts us in all our affliction and thus enables us to comfort those who are afflicted with the same consolation we have received from God.

II CORINTHIANS 1:3-4
NEW AMERICAN BIBLE

Although palliative care is related to hospice care, the two are not identical. All hospice care is palliative care, but not all palliative care is hospice care. In the United States, hospice care treats patients who are not expected to live longer than six months, offering medical, emotional, and spiritual support. It also offers support to their families.

Palliative care, on the other hand, is offered to anyone with a serious illness — at any age and in all stages of the illness. It can be offered along with treatments aimed at curing the patient. In fact, patients who receive palliative care often heal more quickly.

For those with a progressive illness for which there is no cure, palliative care can help them live life more fully, and in some cases for a longer time, than patients who don't have palliative care. ♦



What is palliative care?

Palliative care or palliative medicine is a form of medical care that provides relief from the symptoms and stress of serious illness, regardless of the diagnosis. Palliative care is for people of all ages at all stages of a serious illness.

The goal of palliative care is to help patients live life as fully as they can by:

1. Controlling pain and other symptoms
2. Setting up treatments consistent with the patient's values and wishes
3. Coordinating care
4. Offering spiritual and other support to patients and their families.

Palliative care provides patients comfort and support using an interdisciplinary team of doctors, nurses, social workers, chaplains, physical and occupational therapists, other professional caregivers, and volunteers. They work together to promote the patient's total well-being.

For those patients for whom there is not a cure, palliative care neither hastens death nor tries to postpone it. As the World Health Organization explains, it affirms life but also knows that dying is a normal part of life.

Contemporary palliative medicine grew out of the hospice movement of care for the dying. In the early 1970s, Dr. Balfour Mount coined the term "palliative care" as a means of providing physical, mental, emotional, social, and spiritual care for any patient at all times during a serious or life-limiting illness, not only for those who were dying. Especially since the 1997 Institute of Medicine report, *Approaching Death: Improving Care at the End of Life*, palliative medicine has become part of the mainstream of patient care.

Today, roughly two-thirds of hospitals in the U.S. have palliative care teams, and the number increases every year. It is now an important part of the high quality, person- and family-centered care that many patients have come to expect. Yet the idea behind palliative care is not really new. It is simply caring for the whole person and his or her family.

How do I know if palliative care is right for me or a loved one?

There are many reasons why patients choose palliative care. Perhaps the most important is that palliative care helps you live better with your illness. In addition to assessing and treating physical and psychological symptoms of illness, palliative care can help relieve emotional and spiritual distress by providing resources and support for you and your family. Palliative care also helps with pain control and other symptoms of illness such as fatigue, shortness of breath, nausea, trouble sleeping, loss of appetite, anxiety, depression or spiritual distress.

Another important benefit of palliative care is the ongoing support you receive from an interdisciplinary team of medical specialists who provide information about types of treatments and coordinate all aspects of care. The team works on your behalf throughout the entire course of illness.



Patients today often look to medical specialists for help when they have a serious or chronic illness. In many cases, patients may have complications from other chronic diseases or interacting conditions. Palliative care can be especially helpful in coordinating and managing your care. The palliative care team helps facilitate communication among hospital staff, patient and family about the nature of the illness, its likely progression and the likelihood of death if the patient has a progressive illness.

If your disease is curable, palliative care can help you heal more quickly through symptom relief and emotional and spiritual support. The team can also assist you and your family in establishing treatment plans consistent with your values and wishes. This includes potential changes in treatment that may become necessary as chronic illness progresses and throughout the entire course of the illness.

Does choosing palliative care mean that I or my loved one can no longer be cured?

No, not necessarily. Some people think when they choose palliative care that they can no longer be cured. Often the exact opposite is true. Palliative care is simply caring for the whole person. This is the sort of care that all patients deserve at all times in their illness.

As we have seen, palliative care can actually help you heal more quickly by understanding the illness and relieving pain and the side effects of treatment.

For those with a chronic progressive illness for which there is no cure, palliative care in combination with other treatments can help you live as fully as you can, sometimes for a longer time compared to patients who do not receive palliative care. As the illness progresses the goals of care may change,

and at some point, you may choose to rely totally on comfort-focused treatment. Regardless of changes in prognosis or condition, the palliative team continues to support you and your family throughout the entire course of the illness.

Can I have other medical treatments along with palliative care?

Yes. Palliative care can be offered along with other medical treatments whose purpose is to cure the patient. You do not have to choose one or the other. The palliative care team can also help you see how treatments correspond to your own goals and preferences.

When in my illness do I choose palliative care? How do I get palliative care?

The sooner the better. Palliative care is best begun as soon as possible after the diagnosis of a serious disease so that you and your family may benefit early from the support and benefits it provides. It is available for any serious disease and is not restricted to end-of-life care.

In most instances, it is rather easy to begin palliative care by simply asking the physician or nurse for a referral to the palliative care team. Sometimes, the physician, nurse or another member of the clinical team may suggest palliative care to you. Today some hospitals have automatic referrals for certain diseases such as cancer, heart, liver, or respiratory failure.

After the request has been made, a member of the palliative care team will visit you for palliative care screening. The screening helps develop the palliative care treatment that reflects your values and wishes, the type of symptom relief that might be needed, or other support that might be helpful.

We seek to do more than merely cure a physical illness. Like Jesus, we heal the whole person. We care for people in such a way that, whether or not we can physically cure their illness, they find strength and comfort in knowing God's abiding love for them, despite their experience of chaos.

CARDINAL JOSEPH BERNARDIN

(LATE ARCHBISHOP OF CHICAGO)

A SIGN OF HOPE

Can my family be involved in palliative care treatment?

Yes. Since palliative care focuses on the whole person, it is important to involve family members and others who are an important part of your life. Palliative care can support family members in dealing with the stress and worry they experience when a loved one is seriously ill. It can also help family members who are directly involved in caring for the chronically ill patient know what to expect and how they can access additional education, support, and respite care.

Can I receive palliative care only in a hospital? What happens if I am released from the hospital?

You may receive palliative care in variety of settings. Currently, hospitals are the most common setting for palliative care. Some large hospitals even have specialized palliative care units.



However, it is becoming more common to find that palliative care is available in clinics, long-term care facilities, nursing homes, assisted living facilities, doctors' offices, and even in the home. While most nursing homes and long-term care facilities have an established hospice program, many also have access to staff trained in palliative care screening, assessment, and treatment. These facilities either have a palliative care team of their own in addition to the hospice program, or they work with a consultation team. These teams perform the same function as hospital palliative care teams. Community-based palliative care programs are also being developed for seriously ill people who are not yet candidates for hospice care.

Can I keep my own doctor if I choose palliative care?

Yes. Palliative care is not a substitute for the normal medical treatment that you receive from your doctor or medical specialist. It is an added level of medical, psychological, emotional, and spiritual support. It is often used along with treatments whose purpose is to cure the patient. Your primary doctor and any other doctors you choose will continue to take care of you together with the palliative care team. The palliative care team offers support both to you and to your doctor in caring for you. ♦

Will those involved in palliative care honor my religious beliefs?

Yes. Part of the support that the palliative team provides is spiritual comfort and support.

The team understands and honors the importance of individual spiritual and religious concerns for you and your family. That's why, chaplains are part of the palliative care team. Chaplains can help you explore how your spiritual beliefs and values can be a helpful resource as you experience serious illness. If you wish, they will also provide prayer and spiritual support to help you cope better with chronic progressive illness. The palliative care team respects your personal beliefs and will not impose religious practices on you.

To help the palliative care team serve you, you may be asked to complete a spirituality assessment. The assessment is designed to understand what gives meaning to your life, what brings you comfort, and how your illness affects how you see your life, especially if you are facing a life-limiting illness. Your palliative care team will respect your religious and spiritual beliefs, including the fact that you may not be religious.

What does the Catholic Church say about palliative care?

The Catholic Church values and endorses palliative care. Although palliative medicine is a recently-named specialty in medicine, many

Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age. Indeed, the person, under any circumstances, is an asset to him/herself and to others and is loved by God. This is why, when their life becomes very fragile and the end of their earthly existence approaches, we feel the responsibility to assist and accompany them in the best way.

POPE FRANCIS

ADDRESS TO PARTICIPANTS AT PLENARY OF PONTIFICAL ACADEMY OF LIFE, MARCH 5, 2015

features of palliative care have been a part of medicine — and of Catholic Church teaching — for centuries. The Catholic Church affirms the morality of using medicines to lessen pain, even in the rare cases that these medicines might shorten one's life. The Catholic bishops' *Ethical and Religious Directives for Catholic Health Care Services* explain that "patients should be kept as free of pain as possible" (Directive 61). Similarly, in his encyclical, *The Gospel of Life*, Pope Saint John Paul II reaffirmed the teaching of Pope Pius XII and stated that it is proper "to relieve pain by narcotics, even when the result is decreased consciousness and a shortening of life" (par 65).



All recent popes, from Saint John Paul II to Francis, have endorsed palliative care. In his encyclical, *The Gospel of Life*, Pope Saint John Paul II explained that “palliative care makes suffering more bearable.” He added that it “aims, especially in the case of patients with terminal diseases, at alleviating the vast gamut of symptoms of physical, psychological and mental suffering” (par 65).

In his 2007 “World Day of the Sick Message,” Pope Benedict XVI added that palliative care is “integral care, offering the sick the human assistance and spiritual accompaniment they need.”

Addressing the Pontifical Academy of Life in 2015, Pope Francis described palliative care as “an expression of the truly human attitude of taking care of one another, especially of those who suffer. It is a testimony that the human person is always precious, even if marked by illness and old age.”

The Catholic bishops of the United States have also spoken about palliative care. In their statement, “To Live Each Day in Dignity,” the bishops stressed that palliative care shows “a readiness to surround patients with love, support, and companionship, providing the assistance needed to ease their physical, emotional, and spiritual suffering. This approach must be anchored in unconditional respect for their human dignity, beginning with respect for the inherent value of their lives.” Many other faith traditions have issued similar statements. ♦

Is palliative care the same as hospice care?

No. Palliative care and hospice are not exactly the same. Although all hospice care is palliative care, not all palliative care is hospice care.

Hospice care is both a plan of care at the end of life and a medical insurance benefit plan. It is a form of palliative care that addresses pain reduction, comfort-focused treatment, and emotional and spiritual support for patients with a terminal illness who are not expected to live longer than six months. The hospice movement began in Great Britain by Dame Cicely Saunders in the 1950s.

In the United States, there are at least two important differences between palliative care and hospice care:

1. Although palliative care is available to all persons at all stages of an illness and may be continued throughout chronic illness, hospice care is limited to patients at the end of life, with a life-expectancy of six months or less.
2. Some hospice programs have begun combining palliative care with at least certain forms of curative treatments in certain circumstances. In order to qualify for the Medicare Hospice Benefit, however, the patient or surrogate must agree to give up Medicare coverage for further treatments aimed at curing the disease.

Is “aid in dying” or physician-assisted suicide an option in palliative care?

No. Physician-assisted suicide is not compatible with the life-affirming values of palliative care. “Aid in dying” or physician-assisted suicide takes place when a doctor provides a patient confronted with life-limiting illness with the information and the means (usually pills) necessary for the patient to take his or her life. Some people see this as a way to preserve their dignity or autonomy or a way not to be a burden to others. Several states have legalized this option, and many more are considering making physician-assisted suicide legal either by legislation or referendum.

Many believe that “aid in dying” and palliative care are opposed to each other. Rather than assisting in dying, palliative care offers appropriate pain and symptom control, good communication, and emotional and spiritual support, in order for the patient to live life as fully as possible. Palliative care teams believe that this personal, holistic support is the compassionate care that vulnerable patients truly need, as opposed to assistance in dying.

It is important to note that “aid in dying” or physician-assisted suicide should not be confused with the right of patients to refuse treatments that do not help them. The *Ethical and Religious Directives for Catholic Health Care Services* explain that “the free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless contrary to Catholic moral teaching” (Directive 59). There is an ethical difference between refusing treatment that no longer benefits a patient and providing the means to kill the patient. Palliative care continues to be life-affirming care.



What does the Catholic Church say about tube feeding at the end of life?

The church recognizes the possible burdens and benefits of tube feeding. The purpose of food and water is to help supply the nutrition to the body to help sustain life. When this occurs by means of a tube into the stomach or by IVs, it is called medically assisted nutrition and hydration. To the extent that such assistance benefits the patient, it should be continued.

However, especially at the end of life, when the body is no longer able to process food and water or when their use becomes burdensome for the patient, using medically assisted nutrition and hydration becomes morally optional. This is not the same as “starving” the patient. These patients are unable to eat because they are dying. Their death is not caused by not eating. Food and liquids are no longer fulfilling their purpose of nourishing the patient and may be causing additional discomfort or pain.

The Ethical and Religious Directives for Catholic Health Care Services emphasize the general moral obligation to provide nutrition and hydration, even when administered medically, but it also explains that someone can reject these measures “when they cannot reasonably be expected to prolong life or when they would be excessively burdensome to the patient” (Directive 58). If medically assisted nutrition and hydration do not benefit the patient, the duty remains to care for the patient in other ways. For example care givers can keep the patient’s mouth moist with ice chips, a sponge, or oral swabs. They continue to deal with relief of pain and other symptoms and attend to the patient’s spiritual and emotional needs.

What does “palliative sedation” mean? Is this approved by the Catholic Church?

The church supports measures to relieve pain. There are times when, even with good symptom management, a patient continues to experience unbearable pain and suffering. In these situations, medication can be used to make the patient unconscious in order to relieve the symptoms. This is called palliative sedation. This is used only as a last option, with careful and thoughtful discussion and informed consent. The *Ethical and Religious Directives for Catholic Health Care Services* state that a person “should not be deprived of consciousness without a compelling reason” (Directive 61). Unbearable pain and suffering, however, can be compelling reasons to deprive a person of consciousness.

*The task of medicine is to care
even when it cannot cure.*

**ETHICAL AND RELIGIOUS
DIRECTIVES FOR CATHOLIC
HEALTH CARE SERVICES**
INTRODUCTION TO PART V

Killing the Pain and Not the Patient, a document of the Office of Pro-Life Activities of the United States Conference of Catholic Bishops, explains: “Very rarely it may be necessary to induce sleep to relieve pain and other distress in the final stage of dying... In competent medical hands, sedation for imminently dying patients is a humane, appropriate and medically established approach to what is often called ‘intractable suffering.’ It does not kill the patient, but it can make his or her suffering bearable.” ♦

For more information:

This is one of a series of publications from the Catholic Health Association to help patients, families and caregivers with decisions about end-of-life care. We invite you view the accompanying guides, available in English and Spanish, for additional assistance.



These and other resources are available to order or download at www.chausa.org.



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