



PALLIATIVE AND HOSPICE CARE

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*Living Well with  
Serious Illness*



## **PREFACE**

The Catholic Health Association developed this guide as part of a series of publications to help patients, families, clinicians and caregivers with decisions about serious illness and end-of-life care.

It was created in collaboration with physicians, nurses, theologians, and ethicists within Catholic health care to help people of all ages, backgrounds, religious traditions and beliefs learn about the range of support that is available to patients and families to assist with serious illness.

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## INTRODUCTION

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*Advances in medical treatments and support services provide new opportunities for people of all ages with serious illness to live enjoyable and productive lives.*

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This is encouraging news for people who have been diagnosed with cancer, lung diseases, heart or kidney failure, or other serious medical conditions.

Yet, having a serious illness can be extremely challenging physically, emotionally, spiritually, and/or financially.

There are many questions and concerns:

- + What are my treatment options?
- + Whom can I turn to for help?
- + What resources and support are available?
- + How can I access them?

This booklet will answer these questions to help you enjoy and live life as fully as possible.

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*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.*



## What is palliative care?

Palliative care is a specialized area of medicine that focuses on caring for the whole person — physically, emotionally, socially and spiritually — to relieve the range of symptoms and stress that often accompany serious illness or side effects of treatment.

It is available to everyone with a serious illness — children, teens, adults and the elderly — throughout all stages of disease, regardless of the type of illness or diagnosis.

An interdisciplinary team of doctors, nurses, social workers, chaplains and other professionals works together on your behalf on an ongoing basis to help you understand your illness, get relief from physical symptoms and make plans for future care. Most importantly, palliative care helps you focus on what matters most to you and your loved ones.

The goals of palliative care are to:

- + Control pain
- + Manage symptoms such as fatigue, shortness of breath, nausea, trouble sleeping, loss of appetite
- + Ensure treatments are consistent with your values and wishes
- + Coordinate care across medical teams and specialists for serious illness and other chronic conditions

- + Offer spiritual and emotional support to patients and their families experiencing stress, anxiety or depression
- + Provide comfort and care when a cure is no longer possible and the end of life is approaching.

Palliative care neither hastens death nor uses unnecessary measures to postpone it, recognizing that dying is a normal part of life.

## Is palliative care new?

Although palliative care is a relatively new specialty area of medicine, the focus on caring for mind, body and spirit has inspired Catholic health care for centuries. This commitment to holistic care continues today and is a cornerstone of our healing mission.

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 during a serious illness, not only for those who were dying. 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 in the United States.

Today, many hospitals in the U.S. have palliative care teams, and the number is steadily increasing. Palliative care services are also offered

in assisted living and long-term care facilities as well as in person's homes.

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

Palliative care is helpful to everyone, regardless of age, throughout each stage of serious illness.

Research shows that palliative care helps most people feel better, experience better health outcomes and often live longer than those who don't have it.

Palliative care focuses on the whole person and all aspects of their care, not just a particular disease.

### **Does choosing palliative care mean there's no hope of a cure?**

Not necessarily. Sometimes people think that choosing palliative care means that they can no longer be cured.

Often the opposite is true. Palliative care can help you heal more quickly by understanding the illness, relieving pain, and helping with the side effects of treatment.

In illnesses that have no cure, palliative care in combination with other medical treatments can help you live as fully as you can, sometimes for a longer time compared to patients who do not receive palliative care. At some point if the illness progresses and there is no possibility of a cure, you may choose to rely totally on

treatment focused on comfort. No matter how your condition changes, your palliative team will continue to support you and your family throughout the entire course of the illness.

### **Can I have other medical treatments along with palliative care?**

Yes. You can receive palliative care and other medical treatments for your condition or illness. You have full access to *both* and do not have to choose one or the other.

### **Can I keep my own doctor?**

Yes. You can keep your primary care doctor, specialists and any other clinicians you choose. They will continue to care for you together with your palliative care team. The palliative care team also offers support to your physicians and medical team members who are caring for you.

### **When do I choose palliative care and how do I get it?**

The sooner the better. That way, you can benefit as soon as possible from the support it provides.

In most instances, you can simply ask your physician or nurse for a referral to palliative care services. Sometimes, the physician, nurse or other member of the clinical team may suggest palliative care to you. Some hospitals have automatic referrals for certain

*“We thank God for the palliative team.  
Without your constant care and concern my mom’s  
transition would have been harder.”*

FAMILY MEMBER OF PALLIATIVE CARE PATIENT

diseases such as cancer, heart, liver, or respiratory failure.

Once the referral has been made, a member of the palliative care team will contact you to discuss a treatment plan that reflects your values, wishes for pain and symptom relief, and support that might be helpful.

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*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

### **How much does it cost? Is palliative care covered by insurance?**

Palliative care is covered in the same way as other medical services, such as cardiology for example. Most insurance plans, including Medicare and Medicaid, cover all or part of palliative care.

### **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 important in your life to help them find support in dealing with the stress and worry when a loved one is seriously ill. Persons who are directly involved in caring for the chronically ill patient will learn what to expect and how they can access additional education, support and respite care.

### **Is palliative care only available in a hospital? What happens if I am released or go home?**

Currently, hospitals are the most common setting for palliative care. Some large hospitals even have specialized palliative care units.

However as time goes on, palliative care is becoming more available in clinics, long-term care facilities, nursing homes, assisted living facilities, doctors' offices, and 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 ready for hospice care.

### **Is palliative care the same as hospice care?**

No. Palliative care and hospice care are not the same. Hospice care is a specific type of palliative care for patients who are not expected to live longer than six months.

The modern hospice movement started in the 1950s in Great Britain led by Dame Cicely Saunders. It became a Medicare benefit in the U.S. in 1982 for care at the end of life. Hospice care focuses on relieving pain, providing comfort-oriented medical treatments along with emotional and spiritual support. Hospice is only for patients with a serious illness who are not expected to live longer than six months.

### **What's the difference between palliative and hospice care?**

Although palliative care is available to all persons at all stages of an illness and may be continued throughout all stages of a serious illness, hospice care is limited to patients who are at the end of life, with six months or less left to live.

In palliative care, patients can continue to receive medical treatments aimed at curing the serious illness. Hospice services are provided when patients have six months or less to live and decide to stop treatments aimed at curing their disease such as chemotherapy, blood transfusions, or dialysis.

### **What kind of insurance coverage is available for these services?**

Palliative care is often covered by medical insurance, sometimes with a copay. Hospice care is free of charge to all Medicare or Medicaid patients.



*“Thank you so much for the help, advice, and time you have given our dad and our whole family. We will forever cherish it.”*

FAMILY MEMBER OF  
PALLIATIVE CARE PATIENT



*“Our experience in your Palliative Care program was a very positive one. I will forever cherish what your team has done for my husband and my family. Thank you for your support and encouragement.”*

## Spouse of Palliative Care Patient

### Will my choices, values and beliefs be respected?

Yes. One of the benefits of palliative care is spiritual comfort and support. Your team respects your personal beliefs and your spiritual and religious concerns. The palliative care team includes chaplains who can help you explore how your spiritual beliefs and values can be a helpful resource as you live with a serious illness and decide what matters most to you if you are facing a life-limiting illness. If you wish, they will also provide prayer and spiritual support to help you cope better with your illness. The palliative care team will not impose any religious practices on you.

### What does the Catholic Church say about palliative care?

The focus on healing mind, body and spirit has been integral to Catholic Church teaching for centuries and continues to guide and inspire our approach to healing.

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* (ERDs) explain that “patients should be kept as free of pain as possible” (Directive 61).

Over the years, Popes from Saint John Paul II to Francis have written positively about palliative care. In his address to the Pontifical Academy of Life in 2015, Pope Francis said:

*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.*

In the United States, the Catholic bishops indicated in their statement “To Live Each Day in Dignity” 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 in support of palliative care.

### **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 occurs when a doctor writes a prescription for a lethal dose of medication to a patient who has six-months or less to live so that the patient can end their life. Physician-assisted suicide is not legal in most U.S. states.

Rather than assisting in dying, palliative care offers relief from pain and symptoms, help in understanding the serious illness, and emotional and spiritual support to live life as fully as possible. Palliative care teams believe that this personal, holistic support is the compassionate care

that seriously ill patients truly need, not assistance in dying.

It is important to note that patients have the right to refuse treatments that do not help them. The *ERDs* 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 a difference between refusing treatment that no longer benefits a patient and providing medications so the patient can end their life. Palliative care is life-affirming care.

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

The Church recognizes the possible benefits and burdens of tube feeding. The purpose of food and water delivered through a tube surgically placed in the abdomen is to give nutrition to the body to help sustain life. When someone is fed by a tube or through a needle in their vein, this is called medically assisted nutrition and hydration. If this type of feeding helps the patient it should be continued.

However, at the end of life, when the body is no longer able to process food and water or when the food and water cause pain or swelling or



*“The support of the palliative care team meant that my child’s pain and symptoms were taken seriously and addressed in a compassionate way. It meant that I also got support for my advocacy for my child and making difficult decisions for his care.”*

PARENT OF  
PALLIATIVE CARE PATIENT



make it harder to breathe, medically assisted nutrition and hydration can be stopped. This is not the same as “starving” the patient. These patients are unable to use food and water because they are dying. Their death is not caused by lack of eating but by the serious illness. Food and liquids are no longer fulfilling their purpose of nourishing the patient and may actually be causing additional discomfort or pain.

The *ERDs* emphasize the general moral obligation to provide nutrition and hydration, even through a tube or needle, 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, caregivers can keep the patient’s mouth moist with ice chips, a sponge or oral swabs. Caregivers can safely offer small tastes of the patient’s favorite foods. They continue to deal with relief of pain and other symptoms and attend to the patient’s spiritual and emotional needs.

We continue to care for the patient even when a cure is no longer possible.

## **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 who is nearing the end of life continues to experience severe pain, shortness of breath, or other symptoms that do not get better with medications. In these situations, sedating medications can be used to make the patient unconscious to relieve these symptoms. This is called palliative sedation.

This is used only as a last option, with patients who are nearing death, and with careful and thoughtful discussion and informed consent.

The *ERDs* state that a person “should not be deprived of consciousness without a compelling reason” (Directive 61). Unbearable pain and other severe symptoms, however, can be compelling reasons to use sedating medications to relieve the patient’s symptoms.

**WHERE CAN I FIND OUT MORE  
ABOUT PALLIATIVE CARE AND HOSPICE CARE?**

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We hope you find this information helpful. To view additional resources, publications and articles, visit [chausa.org/palliative/palliative-care](https://chausa.org/palliative/palliative-care).

In addition to asking your physician or health provider, here are additional resources and organizations that can be helpful.

Catholic Health Association

[Chausa.org](https://chausa.org)

[Chausa.org/palliative/palliative-care](https://chausa.org/palliative/palliative-care)

Get Palliative Care

[GetPalliativeCare.org](https://getpalliativecare.org)

Caring Info – National Hospice and Palliative Care Organization

[CaringInfo.org](https://caringinfo.org)

*“Our experience of palliative care was that the team was very supportive, thoughtful, caring and showed concern for our family. Please continue to treat the patients like they are your family. It makes all the difference.”*

**FAMILY OF PALLIATIVE CARE PATIENT**



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The mission of Catholic Health Association of the United States (CHA) is to advance the Catholic health ministry of the United States in caring for people and communities.

Catholic health care is a ministry of the Catholic Church continuing Jesus' mission of love and healing in the world today. Composed of more than 600 hospitals and 1,600 long-term care and other health facilities in all 50 states, the Catholic health ministry is the largest group of nonprofit health care providers in the nation.

At the national level, these organizations join together in the Catholic Health Association of the United States.

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