A Catholic Guide to Palliative Care and Hospice

RESOURCES FOR APPLYING CHURCH TEACHING TO RELIEVE PAIN AND SUFFERING

The National Catholic Bioethics Center fields approximately fifteen hundred ethics consultations each year, and a growing number of them involve palliative care and hospice. From our own experiences with these consults, it is clear that many faithful Catholics are confused about these topics. Inaccurate assumptions—"If I receive palliative care, I won't be treated for my condition"—are fairly common. So is downright error—"I don't want to go to hospice, because that's where they kill people." While abuses do exist, these false perceptions give palliative care and hospice a bad name and can militate against one's receiving quality health care at the end of life. This guide seeks to overcome the confusion and misperceptions by defining what palliative care and hospice actually are, identifying the services they offer, and explaining the similarities and differences between them. The guide also identifies a number of the ethical challenges facing the hospice field, and the insert offers example questions that family members should ask when choosing a hospice organization for a loved one.



Palliative Care

The following definition is taken from the National Consensus Project for Quality Palliative Care: "Palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families, and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care professionals. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family."[1]

There are a number of important points in this definition. First, palliative care is primarily concerned with anticipating, preventing, and managing the physical symptoms (pain, fatigue, and nausea) that result from either an illness itself or the interventions used to treat it. However, relief of physical symptoms is not the only understanding of palliative care. Patients can also experience psychological, emotional, and spiritual symptoms resulting from the storm of illness, and palliative care seeks to address these realities as well. Catholic Tradition maintains that the health of the spirit is essential to the health of the body. Thus palliative care teams can include behavioral health professionals as needed, and those in Catholic hospitals often include a chaplain whose primary purpose is to ensure that patients' spiritual (including sacramental) needs are met.[2]

Second, palliative care seeks to improve a patient's quality of life: what is most important to the patient, what "living well" means within the context of the patient's particular illness or disability.[3] In many cases, patients who experience a serious illness are unable to do what they had been able to do before they became ill.[4] Nonetheless, by alleviating physical symptoms and addressing psychological and spiritual concerns, palliative care seeks to allow patients the opportunity to engage in meaningful and fulfilling activities in light of their medical condition. Such activities can include spending time with family members (especially grandchildren), reading the book they always wanted to read, or repairing relationships with God and others.

Third, palliative care fosters collaboration among health care professionals. Health care today is highly specialized. When patients enter a hospital, they are often treated by a team of physicians, including cardiologists, oncologists, and so on, who focus on a specific aspect of their care. Unfortunately, specialization can lead to fragmentation, which, in turn, can lead to a lack of coordination among specialists. Fragmentation and lack of coordination are realities that palliative care seeks to overcome by taking a holistic view of a patient's care and, in doing so, recognizing the big picture. It can then coordinate the care plan among various specialties to promote the patient's overall good.[5]

Fourth, palliative care is offered in any care setting. Many people are under the impression that palliative care is only for the elderly, the terminally ill, or those who are very close to death. This perception is false. In reality palliative care is appropriate for any patient who is experiencing symptoms due to illness. This includes the terminally ill, but it also includes patients with chronic, life-limiting conditions (heart disease, diabetes, etc.) regardless of their prognosis or treatment options. Many people also believe that by accepting palliative care, one forgoes any intervention to address the underlying illness. Again this perception is false. Palliative care is delivered in conjunction with aggressive medical interventions (e.g., chemotherapy) that treat and actively seek to cure the patient's underlying medical condition. Overall, palliative care is not reserved for one specific group or purpose; it exists for the benefit of all who suffer. Mitigating the negative effects of physical, psychological, and spiritual symptoms is a moral good.[6]

Finally, it is essential to point out that palliative care extends to the patient's entire support network as well. One of the primary goals of palliative care (and hospice) is to take as much of the burden of care as possible off of the patient's family. This is done by alleviating symptoms (physical, psychological, spiritual) and working to improve the patient's overall quality of life. However, family members can also experience suffering and distress as they witness the declining trajectory of their loved one's illness or anticipate his or her death. Behavioral health and spiritual care services can and should be extended to these people as well, both before and after the patient dies.

The Catholic Church supports palliative care and although caution and moral discernment are essential, it encourages the faithful to employ these services when necessary. In 2020, the Congregation for the Doctrine of the Faith (CDF) spoke to the importance of palliative care in *Samaritanus bonus*. It stated that palliative medicine "constitutes a precious and crucial instrument in the care of patients during the most painful, agonizing, chronic and terminal stages of illness." It then pointed out that palliative care is an "authentic expression" of the human and Christian duty to care, and it is a "tangible symbol of the compassionate 'remaining' at the side of the suffering person." However, the CDF also warned about challenges associated with palliative care. In some counties, it is provided along with euthanasia and assisted suicide (euphemistically termed medical aid in dying), a reality that may cause confusion as people might come to believe that these immoral practices are permissible. In addition, some palliative care professionals utilize interventions that, while claiming to relieve suffering, directly hasten death. These include the over-administration of medications (especially opioids) and the withholding or withdrawing of nutrition and hydration.[7]

> Patients can experience psychological, emotional, and spiritual symptoms resulting from the storm of illness. Palliative care seeks to address these realities.

The United States Conference of Catholic Bishops (USCCB) also addressed palliative care in the seventh edition of the *Ethical and Religious Directives*. Directive 61 states, "Catholic health care services should strive to support those who suffer from life-limiting illness … with the full range of multidisciplinary palliative care in order to address suffering that may be physical, psychological, and spiritual." Here the bishops affirmed the multi-faceted dimension of palliative care and expressed Catholic health care's positive moral duty ("should strive to support") to provide palliative care services for its patients. They continued in the Directive by stressing the importance of "walking with" patients who experience suffering: "While such [palliative] care includes effective pain relief therapy and symptom management, it also includes personal accompaniment, to counteract the isolation and loneliness that they may experience." The bishops here point to the importance of the beyond-physical symptoms aspects of palliative care and their call to 'accompaniment' will be further addressed below.

Hospice

The National Coalition for Hospice and Palliative Care defines hospice as "a specific type of palliative care provided to individuals with a life expectancy measured in months, not years." It adds, "Hospice teams provide patients and families with expert medical care, emotional, and spiritual support, focusing on improving patient and family quality of life."[8] This brief definition demonstrates that hospice shares a number of similarities with palliative care. Both focus on symptom management, including physical, emotional (psychological), and spiritual support. Both are provided by interdisciplinary teams, emphasize quality of life, and serve the patient and family members. In addition, both can be provided in a variety of settings, including assisted-living and long-term care facilities (nursing homes), rehabilitation centers, clinics, and at home.[9]

However, there are important differences between hospice and palliative care. First, while palliative care is appropriate for any patient, hospice focuses on patients with

a life expectancy of six months or less. As such, it is often referred to as "palliative care for the terminally ill."[10] Second, hospice generally is not provided in conjunction with curative interventions. Patients enter hospice with the knowledge that they will no longer receive treatments, medications, or procedures that seek to cure their underlying medical condition.[11] In fact, patients are generally admitted to hospice when (1) their terminal medical condition no longer responds to aggressive interventions, or (2) they have chosen (for ethically appropriate reasons) to discontinue medical interventions.[12] A third difference is that, unlike much of palliative care, hospice is a covered, regulated health care benefit. Medicare, Medicaid, and most health insurance programs cover hospice services for their members. These services include, but are not limited to, medications and other supplies necessary for end-of-life care (oxygen, durable medical equipment, etc.), education on pain and symptom control and medication management, visits from hospice representatives (nurses, social workers, chaplains, and volunteers), ongoing emotional and spiritual support for the patient, and bereavement support for family members.

As with palliative care, the Catholic Church is very supportive of hospice, as evidenced by statements from three recent popes. (The following quotes use the term palliative care, but the context suggests that the authors are referring to hospice.) In 2004 Pope St. John Paul II stated that in situations where curative interventions are no longer possible, methods of palliative care are required. Such methods "seek to make suffering more bearable in the final stages of illness and to ensure that the patient is supported and accompanied in his or her ordeal."[13] In 2006 Pope Benedict XVI maintained that the Church "[urges] improved care" for terminally ill patients, and he stressed "the need for more palliative care centres which provide integral care, offering the sick the human assistance and spiritual accompaniment they need."[14] In 2015 Pope Francis echoed his predecessors by explaining, "Palliative care is an expression of the truly human attitude of taking care of one another, especially of those who suffer. … The objective of palliative care is to alleviate suffering in the final stages of illness and at the same time to ensure the patient [has] appropriate human accompaniment."[15]

The CDF and USCCB have also emphasized the importance of hospice in more recent years. In *Samaritanis bonus* (2020), the CDF stated that hospice centers "provide an important and valuable service" and are examples of "genuine humanity in society." When hospice professionals provide care in accord with Christian faith, they accompany patients in their experience of pain and (hopefully) open them to a "trusting hope." In this way, hospice centers constitute "sanctuaries where suffering is full of meaning."[16] In Directive 62 of the revised ERDs the US bishops state that Catholic health care has a duty to provide patients "in the final phase of life" with end-of-life care consonant with the teachings of the Church, care that includes "psychological, communal, and spiritual support" for both patient and family members. While not specifically using the term, the directive is clearly speaking about hospice. The bishops also state that such care should be provided "in the most suitable environment" which includes at home, in a nursing home, or at a dedicated hospice center. Here is the explicit recognition that hospice can be practiced in various settings, preferably the one chosen by the patient that best meets his or her needs. In line with this, the directive states that such care should facilitate as much as possible the patient's contact with family, friends, and faith community because the patient—even when dying—remains a member of these communities. Finally, as they did with palliative care, the bishops speak to the importance of accompanying patients at end-of-life: "every effort should be made to maintain [patients'] relationships to counteract the isolation and loneliness that they may experience."

It is notable that John Paul II, Benedict XVI, Francis, the CDF, and the USCCB each used the word accompaniment or a similar term when speaking about palliative care and hospice. This is not a coincidence. Catholic Tradition maintains that a person's death is the most profound moment of his or her life. It is the moment when an individual transitions from this existence into eternity and hopefully into full communion with God. This moment, and others leading up to it, can be a time of great fear and anxiety. Christians have a moral duty to accompany their loved ones on the road to death and, if possible, to be with them when their earthly existence is fulfilled. Hospice and palliative care provide a means to fulfill this duty. By alleviating suffering, they offer meaningful ways "to create a loving presence around the dying person" so that "hope may prevail over anguish."[17]

Cautions with Hospice

Hospice offers life-affirming benefits to individuals who are dying, but only if it is provided correctly. In fact there are serious challenges associated with some hospices. The

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following challenges do not apply to all hospice organizations. However, they are realities within the industry as a whole.

1. Some hospice agencies or direct caregivers do not provide routine (ordinary) care such as anti-biotics for infections when they are indicated, and some unnecessarily withhold medications for chronic conditions such as diabetes, high blood pressure, and so on.

2. Some hospices fail to adequately monitor pain, resulting in the patient's experiencing significant but unnecessary discomfort.

3. Some hospices immediately begin opioid (or similar) medications even when patients are not experiencing pain. They also overmedicate these patients to "keep them calm."

4. Some hospices do not feed (or hand-feed) patients when they are not capable of feeding them-selves, or they do not maintain medically assisted nutrition and hydration (e.g., a feeding tube) when medically indicated. As a result, patients may be dying from dehydration or starvation and not their underlying medical condition. This is a form of passive or indirect euthanasia known as euthanasia by omission. Note that patients with dementia pose particularly difficult challenges in this area. The question of whether to provide nutrition and hydration to a patient who is physically unable to take food and water should be determined on a case-by-case basis.

5. Some hospices advise and practice palliative sedation, understood as deliberately maintaining a patient in an unconscious state through medication until death occurs. While there are limited situations where this practice is permissible, palliative sedation is highly problematic when used to hasten death.[18] It also poses a particular theological and spiritual challenge for Catholics because the Church teaches that patients should remain conscious (to the most reasonable extent possible) to properly prepare for death.

6. Some hospice (and palliative care) organizataions are "opting in" to physician-assisted suicide in states where it is legal. Proponents of assisted suicide and euthanasia are actively working to incorporate these practices into their hospice and palliative care services.

Notes

1. National Consensus Project for Quality Palliative Care (NCP), *Clinical Practice Guidelines for Quality Palliative Care*, 4th ed. (Richmond, VA: National Coalition for Hospice and Palliative Care, 2018), ii.
2. Ibid., 1–2, 32–37; and USCCB, *Ethical and Religious Directives for Catholic Health Care Services*, 7th ed. (Washington, DC: USCCB, 2025), part 2, intro.
3. Quality of life is not a criterion for determining that a life is not worth living, which is the perspective of advocates for euthanasia and physician-assisted suicide.
4. Amy S. Kelley and Evan Bollens-Lund, "Identifying the Population with Serious Illness: The 'Denominator' Challenge," *Journal of Palliative Medicine* 21 suppl 2 (March 1, 2018): 7–16, doi: 10.1089/jpm.2017.0548. *Serious illness* is defined as "a health condition that carries a high risk of mortality AND either negatively impacts a person's daily function or quality of life, OR excessively strains their caregiver" (8, box 1).
5. NCP, *Clinical Practice Guidelines*, 1.3.3.
6. USCCB, *Ethical and Religious Directives*, part 5 intro, dir. 63.
7. Congregation for the Doctrine of the Faith, *Samaritanus bonus: On the Care of Persons in the Critical and Terminal Phases of Life*, 2020, V.4,
8. NCP, *Clinical Practice Guidelines*, iii.
9. Ibid., 5–6.
10. Palliative Care and Hospice Task Force, "Strategic Plan Report," 6.
11. Note: Hospice patients can receive interventions for other medical conditions that do not relate to their terminal diagnosis (i.e. diabetes, hypertension, etc.).
12. See National Catholic Bioethics Center, *A Catholic Guide to End-of-Life Decisions* (Philadelphia: NCBC, 2011).
13. John Paul II, *Evangelium vitae* (March 25, 1995), n. 65, cited in John Paul II, Address to the 19th International Conference of the Pontifical Council for Health Pastoral Care (November 12, 2004), n. 5.
14. Benedict XVI, Message for Fifteenth World Day of the Sick (December 8, 2006).
15. Francis, Address to the Pontifical Academy for Life (March 5, 2015).
16. *Samaritanus bonus*, V. 5.
17. Pontifical Council for Pastoral Assistance to Health Care Workers, *New Charter for Health Care Workers*, English ed. (Philadelphia: NCBC, 2017), n. 147, emphasis original.
18. For information on the morally licit use of palliative sedation, see International Association of Catholic Bioethicists, "The Use of Sedatives in the Care of Persons Who are Seriously Ill or Dying: Ethical Distinctions and Practical Recommendations," *National Catholic Bioethics Quarterly* 12.3 (Autumn 2012): 489–501, doi: 10.5840/ncbq201212331. See also *New Charter for Health Care Workers*, n. 155, and ERD 63.



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Questions to Ask before Enrolling a Loved One in Hospice

HOSPICE NAME: _____

HOSPICE ADDRESS: _____

HOSPICE PHONE NUMBER: _____

HOSPICE CONTACT NAME: _____

1. When was the last time this hospice was reviewed or accredited? What were the results of this review or accreditation? What is the status of the hospice's license?

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2. Will this hospice provide references from prior patients, their family members, or oversight organizations that can be verified?

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3. What is the hospice's communication policy, particularly with regard to the patient's surrogate decision maker and family members? Do the surrogate and family members have access to patient and staff 24/7?

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4. What training does this hospice offer for family members on the proper administration of medications and the use of equipment?

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5. What procedures are in place to ensure that the hospice is not short-staffed, so that a nurse or other caregiver can be summoned by a patient or family member when needed?

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6. Does this hospice provide or have access to spiritual care services, particularly Catholic clergy to administer the sacraments?

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7. Will this hospice treat infections with antibiotics? Will it continue to administer prescribed medications for chronic illnesses?

8. Does this hospice accept patients on dialysis? Will it continue dialysis if renal failure is not the patient's terminal condition?

9. Will this hospice begin an IV if necessary to administer medications or hydration? If not, what procedure is in place to ensure that patients receive an IV if indicated by the patient, surrogate, family member, or physician?

10. What experience does this hospice have with patients suffering from dementia? What is its policy on feeding patients with dementia?

11. Does this hospice accept patients with a feeding tube? Will it transfer the patient to establish a feeding tube to provide nutrition and hydration if indicated by the patient, surrogate, family member, or physician? Under what circumstances would a feeding tube be withheld or withdrawn?

12. What is this hospice's policy on pain management? What monitoring system is in place to determine the effectiveness of pain control? What criteria determine the administration of pain medications?

13. Under what, if any, circumstances would palliative sedation be used?

14. How does this hospice respond to requests for assisted suicide or voluntary stopping of eating and drinking (VSED)?