# 7.3 Death Practices

## What are practices related to death and dying?

In this section, we’ll turn our attention from the process of dying to the actual death of the individual. We’ll examine various ways in which deliberate death can occur, along with the supportive practices that are available for those who are dying. We will also take a closer look at cultural and legal implications of end-of-life practices.

### Learning Objectives

* Explain the philosophy and practice of palliative care
* Describe hospice care
* Summarize Dame Cicely Saunders’ writings about total pain of the dying
* Differentiate attitudes toward hospice care based on race and ethnicity
* Describe and contrast types of euthanasia and physician-assisted suicide

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## Palliative Care and Hospice

### Palliative Care

**Palliative care** is an interdisciplinary approach to specialized medical and nursing care for people with life-limiting illnesses. It focuses on providing relief from the symptoms, pain, physical stress, and mental stress at any stage of illness, with a goal of improving the quality of life for both the person and their family. Doctors who specialize in palliative care have had training tailored to helping patients and their family members cope with the reality of the impending death and make plans for what will happen after (National Institute on Aging, 2019).

Palliative care is provided by a team of physicians, nurses, physiotherapists, occupational therapists, speech-language pathologists, and other health professionals who work together with the primary care physician and referred specialists or other hospital or hospice staff to provide additional support to the patient. It is appropriate at any age and at any stage in a serious illness and can be provided as the main goal of care or along with curative treatment. Although it is an important part of end-of-life care, it is not limited to that stage. Palliative care can be provided across multiple settings including in hospitals, at home, as part of community palliative care programs, and in skilled nursing facilities. Interdisciplinary palliative care teams work with people and their families to clarify goals of care and provide symptom management, psychosocial, and spiritual support.

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### Hospice

In many other countries, no distinction is made between palliative care and hospice, but in the United States, the terms have different meanings and usages. They both share similar goals of providing symptom relief and pain management, but **hospice care** is a type of care involving palliation without curative intent. Usually, it is used for people with no further options for curing their disease or for people who have decided not to pursue further options that are arduous, likely to cause more symptoms, and not likely to succeed. The biggest difference between hospice and palliative care is the type of illness people have, where they are in their illness especially related to prognosis, and their goals/wishes regarding curative treatment. Hospice care under the Medicare Hospice Benefit requires that two physicians certify that a person has less than six months to live if the disease follows its usual course. This does not mean, though, that if a person is still living after six months in hospice he or she will be discharged from the service.

Hospice care involves caring for dying patients by helping them be as free from pain as possible, providing them with assistance to complete wills and other arrangements for their survivors, giving them social support through the psychological stages of loss, and helping family members cope with the dying process, grief, and bereavement. It focuses on five topics: communication, collaboration, compassionate caring, comfort, and cultural (spiritual) care. Most hospice care does not include medical treatment of disease or resuscitation although some programs administer curative care as well. The patient is allowed to go through the dying process without invasive treatments. Family members who have agreed to put their loved one on hospice may become anxious when the patient begins to experience death. They may believe that feeding or breathing tubes will sustain life and want to change their decision. Hospice workers try to inform the family of what to expect and reassure them that much of what they see is a normal part of the dying process.

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### The History of Hospice

Dame Cicely Saunders was a British registered nurse whose chronic health problems had forced her to pursue a career in medical social work. The relationship she developed with a dying Polish refugee helped solidify her ideas that terminally ill patients needed compassionate care to help address their fears and concerns as well as palliative comfort for physical symptoms. After the refugee’s death, Saunders began volunteering at St Luke’s Home for the Dying Poor, where a physician told her that she could best influence the treatment of the terminally ill as a physician. Saunders entered medical school while continuing her volunteer work at St. Joseph’s. When she achieved her degree in 1957, she took a position there.

Saunders emphasized focusing on the patient rather than the disease and introduced the notion of ‘total pain’, which included psychological, spiritual, emotional, intellectual, and interpersonal aspects of pain, the physical aspects, and even financial and bureaucratic aspects. This focus on the broad effects of death on dying individuals and their families has provided the foundation for modern-day practices related to hospice care services (Richmond, 2005).  Saunders experimented with a wide range of opioids for controlling physical pain but also considered the needs of the patient’s family.

Saunders disseminated her philosophy internationally in a series of tours of the United States that began in 1963. In 1967, Saunders opened St. Christopher’s Hospice. Florence Wald, the Dean of Yale School of Nursing who had heard Saunders speak in America, spent a month working with Saunders there in 1969 before bringing the principles of modern hospice care back to the United States, establishing Hospice, Inc. in 1971. Another early hospice program in the United States, Alive Hospice, was founded in Nashville, Tennessee in 1975. By 1977 the National Hospice Organization had been formed.

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### Hospice Care in Practice

The early established hospices were independently operated and dedicated to giving patients as much control over their own death process as possible. Today, it is estimated that over 40 million individuals require palliative care, with over 78% of them being of low-income status or living in low-income countries (World Health Organization, 2019).  It is also estimated, however, that less than 14% of these individuals receive it. This gap is created by restrictive regulatory laws regarding controlled substance medications for pain management, as well as a general lack of adequate training in regards to palliative care within the health professional community. Although hospice care has become more widespread, these new programs are subjected to more rigorous insurance guidelines that dictate the types and amounts of medications used, length of stay, and types of patients who are eligible to receive hospice care. Thus, more patients are being served, but providers have less control over the services they provide, and lengths of stay are more limited. Patients receive palliative care in hospitals and in their homes.

The majority of patients on hospice are cancer patients and they typically do not enter hospice until the last few weeks prior to death. The average length of stay is less than 30 days and many patients are on hospice for less than a week (World Health Organization, 2019). Medications are rubbed into the skin or given in drop form under the tongue to relieve the discomfort of swallowing pills or receiving injections. A hospice care team includes a chaplain as well as nurses and grief counselors to assist spiritual needs in addition to physical ones. When hospice is administered at home, family members may also be part, and sometimes the biggest part, of the care team. Certainly, being in familiar surroundings is preferable to dying in an unfamiliar place. But about 60 to 70 percent of people die in hospitals and another 16 percent die in institutions such as nursing homes. Most hospice programs serve people over 65; few programs are available for terminally ill children.

Hospice care focuses on alleviating physical pain and providing spiritual guidance. Those suffering from Alzheimer’s also experience intellectual pain and frustration as they lose their ability to remember and recognize others. Depression, anger, and frustration are elements of emotional pain, and family members can have tensions that a social worker or clergy member may be able to help resolve. Many patients are concerned with the financial burden their care will create for family members. And bureaucratic pain is also suffered while trying to submit bills and get information about health care benefits or to complete requirements for other legal matters. All of these concerns can be addressed by hospice care teams.

The Hospice Foundation of America notes that not all racial and ethnic groups feel the same way about hospice care. Certain groups may believe that medical treatment should be pursued on behalf of an ill relative as long as possible and that only God can decide when a person dies. Others may feel very uncomfortable discussing issues of death or being near the deceased family member’s body. The view that hospice care should always be used is not held by everyone and health care providers need to be sensitive to the wishes and beliefs of those they serve. Similarly, the population of individuals using hospice services is not divided evenly by race. Approximately 81% of hospice patients are White, while 8.7% are African American, 8.7% are multiracial, 1.9% are Pacific Islander, and only 0.2% are Native American (Campbell et al., 2014).

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## Euthanasia and Physician-Assisted Suicide

**Euthanasia,**or helping a person fulfill their wish to die, can happen in two ways: voluntary euthanasia and physician-assisted suicide. **Voluntary euthanasia** refers to helping someone fulfill their wish to die by acting in such a way to help that person’s life end. This can be **passive euthanasia,**such as no longer feeding someone or giving them food. Or it can be **active euthanasia** such as administering a lethal dose of medication to someone who wishes to die. In some cases, a dying individual who is in pain or constant discomfort will ask this of a friend or family member, as a way to speed up what he or she has already accepted as being inevitable. This can have lasting effects on the individual or individuals asked to help, including but not limited to prolonged (Meier et al., 2009).

**Physician-Assisted Suicide:** Physician-assisted suicide occurs when a physician prescribes the means by which a person can end his or her own life. This differs from euthanasia, in that it is mandated by a set of laws and is backed by legal authority. Physician-assisted suicide is legal in the District of Columbia and several states, including Oregon, Hawaii, Vermont, and Washington. It is also legal in the Netherlands, Switzerland, and Belgium.

### What Do You Think?

What would you do if your spouse or loved one was declared brain dead but his or her body was being kept alive by medical equipment? Whose decision should it be to remove a feeding tube? Should medical care costs be a factor?

On February 25, 1990, a Florida woman named Terri Schiavo went into cardiac arrest, apparently triggered by a bulimic episode. She was eventually revived, but her brain had been deprived of oxygen for a long time. Brain scans indicated that there was no activity in her cerebral cortex, and she suffered from severe and permanent cerebral atrophy. Basically, Schiavo was in a vegetative state. Medical professionals determined that she would never again be able to move, talk, or respond in any way. To remain alive, she required a feeding tube, and there was no chance that her situation would ever improve.

On occasion, Schiavo’s eyes would move, and sometimes she would groan. Despite the doctors’ insistence to the contrary, her parents believed that these were signs that she was trying to communicate with them.

After 12 years, Schiavo’s husband argued that his wife would not have wanted to be kept alive with no feelings, sensations, or brain activity. Her parents, however, were very much against removing her feeding tube. Eventually, the case made its way to the courts, both in the state of Florida and at the federal level. By 2005, the courts found in favor of Schiavo’s husband, and the feeding tube was removed on March 18, 2005. Schiavo died 13 days later.

Why did Schiavo’s eyes sometimes move, and why did she groan? Although the parts of her brain that control thought, voluntary movement, and feeling were completely damaged, her brainstem was still intact. Her medulla and pons maintained her breathing and caused involuntary movements of her eyes and the occasional groans. Over the 15-year period that she was on a feeding tube, Schiavo’s medical costs may have topped $7 million (Arnst, 2003).

These questions were brought to popular conscience decades ago in the case of Terri Schiavo, and they have persisted. In 2013, a 13-year-old girl who suffered complications after tonsil surgery was declared brain dead. There was a battle between her family, who wanted her to remain on life support, and the hospital’s policies regarding persons declared brain dead. In another complicated 2013–14 case in Texas, a pregnant EMT professional declared brain dead was kept alive for weeks, despite her spouse’s directives, which were based on her wishes should this situation arise. In this case, state laws designed to protect an unborn fetus came into consideration until doctors determined the fetus unviable.

Decisions surrounding the medical response to patients declared brain dead are complex. What do you think about these issues?

The specific laws that govern the practice of physician-assisted suicide vary between states. Oregon, Vermont, and Washington, for example, require the prescription to come from either a Doctor of Medicine (M.D.) or a Doctor of Osteopathy (D.O.) (Theil-Reiter et al., 2018). These state laws also include a clause about the designated medical practitioner being willing to participate in this act. In Colorado, terminally ill individuals have the option to request and self-administer life-ending medication if their medical prognosis gives them six months or less to live. In the District of Columbia and Hawaii, the individual is required to make two requests within predefined periods of time and also complete a waiting period, and in some cases undergo additional evaluations before the medication can be provided.

A growing number of the population support physician-assisted suicide. In 2000, a ruling of the U.S. Supreme Court upheld the right of states to determine their laws on physician-assisted suicide despite efforts to limit physicians’ ability to prescribe barbiturates and opiates for their patients requesting the means to end their lives. The position of the Supreme Court is that the debate concerning the morals and ethics surrounding the right to die is one that should be continued. As an increasing number of the population enters late adulthood, the emphasis on giving patients an active voice in determining certain aspects of their own death is likely.

### Physician-Assisted Suicide

In a recent example of physician-assisted death, David Goodall, a 104-year-old professor, ended his life by choice in a Swiss clinic in May 2018. Having spent his life in Australia, Goodall traveled to Switzerland to do this, as the laws in his country do not allow for it. Swiss legislation does not openly permit physician-assisted suicide, but it does not forbid an individual with “commendable motives” from assisting another person in taking his or her own life. Watch this video of a news conference with Goodall [“104-year-old Australian Promotes Right to Assisted Suicide”](https://www.youtube.com/watch?time_continue=47&amp;v=0aoAg3LhYfc) that took place the day before he ended his life with physician-assisted suicide.

Another public advocate for physician-assisted suicide and death with dignity was 29-year old Brittany Maynard, who after being diagnosed with terminal brain cancer, decided to move to Oregon so that she could end her life with physician-assisted suicide. You can watch this video [“The Brittany Maynard Story”](https://www.youtube.com/watch?time_continue=1&amp;v=yPfe3rCcUeQ) to learn more about Brittany’s story.

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## Conclusion

Death is something we all must face at some point. It occurs on physiological, psychological, and social levels, each of which has unique implications for the dying individuals and those close to them. Physiological death occurs as the body ceases to function, eventually rendering the individual unable to engage in basic necessary processes, such as breathing and eating. Psychological death occurs when the individual begins to face his or her impending death and consequently regresses into the self. Societal death occurs when others withdraw from the individual, perhaps unable to effectively cope with the impending loss and its implications. In some cases, palliative care or hospice services are utilized to assist both the dying individual and his or her family throughout the dying process. These services include care for the dying individual, as well as support for the family. In addition, several states allow terminally ill or dying individuals to utilize physician-assisted suicide, in which a medical practitioner prescribes and/or administers life-ending medication at the individual’s request. The utilization of palliative or hospice care services, as well as physician-assisted suicide, vary between individuals, cultures, and racial groups, ultimately reflecting the legal, ethical, and moral complexity of both types of practices.

The way in which we view death, talk about it, prepare for it, and what we do when it happens, vary both within and between cultures. Coping with the grief that is associated with death and loss is a complex but necessary process, with a number of strategies for working through the situation in a healthy and positive way. Several theories have been created to explain how grieving happens, some including stages of grief that the individual experiences, others including tasks that the individual must complete. These stages and tasks on their own are neutral, with the potential to facilitate positive coping, but can also become maladaptive if the individual does not work through them in a healthy way. Death is ultimately the end of lifespan development, an occurrence that takes place for everyone at some time.  It is the culmination of the other stages of development, many of which play a role in shaping how the individual handles death when the time comes, both for the self and for loved ones.

## Additional Supplemental Resources

### Websites

* [National Alliance for Grieving Children](https://childrengrieve.org/)
	+ The NAGC is a nationwide network comprised of professionals, institutions, and volunteers who promote best practices, educational programming, and critical resources to facilitate the mental, emotional and physical health of grieving children and their families.

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### Videos

* [The Brittany Maynard Story](https://www.youtube.com/watch?time_continue=1&amp;v=yPfe3rCcUeQ)
	+ In October 2014, 29-year-old Brittany Maynard told the world she planned to die gently with dignity before brain cancer completely destroyed her body and mind.
* [The Science of Aging](https://www.youtube.com/watch?v=BkcXbx5rSzw)
	+ Why do we age, from a biological perspective?
* [Being Mortal (full film) | FRONTLINE](https://www.youtube.com/watch?v=lQhI3Jb7vMg)
	+ How do you talk about death with a dying loved one? Dr. Atul Gawande explores death, dying, and why even doctors struggle to discuss being mortal with patients, in this Emmy-nominated documentary.
* [Age & Aging: Crash Course](https://www.youtube.com/watch?v=kJ18whKduFo)
	+ People are getting older – not just in the individual sense, but the human population itself. Today we’re going to explore those shifting patterns and their implications. We’ll go over the biological, psychological, and cultural aspects of aging, including some of the particular challenges that older
* [What Makes a Good Life? Lessons from the Longest Study on Happiness](https://www.ted.com/talks/robert_waldinger_what_makes_a_good_life_lessons_from_the_longest_study_on_happiness?language=en)
	+ What keeps us happy and healthy as we go through life? If you think it’s fame and money, you’re not alone – but, according to psychiatrist Robert Waldinger, you’re mistaken. As the director of a 75-year-old study on adult development, Waldinger has unprecedented access to data on true happiness and satisfaction. In this talk, he shares three important lessons learned from the study as well as some practical, old-as-the-hills wisdom on how to build a fulfilling, long life.
* [Brené Brown on Empathy](https://www.youtube.com/watch?v=1Evwgu369Jw)
	+ What is the best way to ease someone’s pain and suffering? In this beautifully animated RSA Short, Dr. Brené Brown reminds us that we can only create a genuine empathic connection if we are brave enough to really get in touch with our own fragilities.
* [We don’t “move on” from grief. We move forward with it | Nora McInerny](https://www.youtube.com/watch?v=khkJkR-ipfw)
	+ In a talk that’s by turns heartbreaking and hilarious, writer and podcaster Nora McInerny shares her hard-earned wisdom about life and death. Her candid approach to something that will, let’s face it, affect us all, is as liberating as it is gut-wrenching. Most powerfully, she encourages us to shift how we approach grief. “A grieving person is going to laugh again and smile again,” she says. “They’re going to move forward. But that doesn’t mean that they’ve moved on.

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