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## **Choices as the End of Life Approaches**

Death is inevitable. For most people, it results from conditions and diseases that are managed over weeks or months, sometimes years. But even after someone is given a diagnosis of a mortal condition, the remaining months, weeks or days of life can still be rich and fulfilling. As the end of life approaches the quality of life is best preserved by harmonizing social, spiritual, psychological, and health care support.

Many people, upon understanding they have a terminal condition, speak of a deepening moment-to-moment sense of life and connection to the people who matter most to them. They feel that the time remaining is precious and want to share it with those they love. The involvement of the family and friends as well as those groups and communities that have been meaningful for the patient and their loved ones can contribute to this *harmony of care* by providing attention, assistance, and support. Spending time with a person as the end of their life approaches can be a fulfilling spiritual and emotional experience.

These are times when family and friends can interact with love and express deeply felt emotions. Stories and memories can be shared. Brothers and sisters, children, grandchildren, and others can “make up for lost time”, perhaps heal old wounds. In the final month of his life, my father told me stories of his experiences as a younger man that he had never shared before. He clearly had an ease and interest not felt before in sharing these old memories. It left me with a broader understanding of his life. It provides an enduring sweet and warm memory of him, and our time together in those final days before his death.

These last days of life can be an opportunity for understanding and resolution. It can be a time when expressions of love and intimate sharing become a priority over more material or mundane concerns. Oliver Sacks, the well-known neurologist, and best-selling author, on learning he had terminal cancer wrote:

*“Over the last few days, I have been able to see my life as from a great altitude, as a sort of landscape, and with a deepening sense of connection of all its parts. This does not mean I am finished with life.*

*“On the contrary, I feel intensely alive, and I want and hope in the remaining time to deepen my friendships, to say farewell to those I love... and to achieve new levels of understanding and insight.*

*“This will involve audacity, clarity and plain speaking. But there will be time, too, for fun.*

*“I feel a sudden clear focus and perspective.”*

The patient and the family can make choices for the support that will best provide an opportunity to spend this valuable time together. The preferences of the patient and the family in addition to the condition of the person nearing death can influence greatly how this final part of life is experienced. Pain, cognitive abilities, alertness, and other physical and emotional conditions will likely influence the choices that are made as a person nears their death.

To maximize the opportunities of having rich experiences at the end of life with family members, partners, and other significant people it is important that the patient is in an environment that is welcoming and accepting of their particular values and identities. A leader in the LGBTQ (lesbian, gay, bisexual, transgender, and queer) community told me that fellow members express particular concerns about judgment or condemnation of their orientations and identities. These can cause fear, tension, or sadness and inhibit open interactions. This may lead to isolation and make it difficult to share feelings and concerns openly. These fears may cause a patient to refuse services and support that can provide an environment that is caring and dignified at the end of life.

Service providers and staff from facilities that have the cultural competence to understand diverse backgrounds and interests, increase the opportunity for maximizing the quality of time remaining in a person's life. Religious beliefs, ethnic identity, sexual orientation, gender identity, and other culturally based values and experiences need to be honored and accepted to achieve a true harmony with all areas of a patient's care. This may require support from their own community in making sure these sensitive needs are respected. There are organizations that provide training in particular cultural competences and can provide information about suitably trained providers. An example of this for the LGBTQ community is SAGE (Services and Advocacy for Gay, Lesbian, Bisexual and Transgender Elders; <http://sageusa.care/>). There are other organizations that offer support for particular ethnic and religious groups.

Frequently there is a sort of fog that descends on patients, their families, and care providers when they are in this challenging period near the end of life. There is often a lack of clarity regarding the trajectory of the medical condition or illness and what the benefits and burdens that any intervention may bring. Obtaining support and advice from care givers and community members who have experience of this important period can be invaluable.

You have choices as the end of life approaches. Your care and support may be done at home or in another facility. You can choose to stop all life-sustaining treatments. This means you can discontinue any treatment already in place, such as a feeding tube, medications, breathing assistance, chemotherapy, antibiotics, dialysis, blood transfusions, etc. You can ask that a pacemaker be turned off. You can decide not to initiate new treatments. *This does not mean medications or treatments that can control pain or treat other discomforts are eliminated.*

People want to be in control of decisions about their own care. Yet frequently at the end of life, there are numerous factors that can work against realizing this. Many people nearing the end of life are no longer sufficiently alert or may have physical and cognitive impairments that make it difficult to express their choices. It may be difficult to recognize that the end of life is approaching. It is important to have conversations about end-of-life choices with health care providers, family, and a chosen advocate well in advance. Yet such discussions frequently do not take place because we wait for the doctor or the family members to initiate them. Even when they do take place, there can be confusion, or it may be emotionally difficult to invoke any preferences or decisions that had been discussed previously. Advance Directives and other care planning choices made earlier may need to be reviewed at this time by the patient and family members and the chosen person to be in charge of invoking the decisions (see Chapter 9).

Stopping treatments or asking to be discharged from a hospital or another institution is your right, yet may be met with resistance. This reluctance to end support and treatment that prolongs life is understandable. Hospitals and other such establishments were founded to help heal, to treat disease, and to prolong life. There is also an interest to make certain that the placement and resolution for a patient in their care is reasonable, safe, and comfortable. This can delay implementing the choices the patient and the family insist on. Sometimes there are religious beliefs that enter into this resistance. So stopping treatments or leaving a facility may feel to those service providers, based on their training and experience, not to be following the safest course.

There are also financial incentives in medical establishments for continuing treatments. Nowadays, about 25-30% of all Medicare outlays are for care in the last year of beneficiaries' lives. This means that people nearing death are typically having medical interventions, often in hospitals and intensive care units that are costly. These interventions, by definition, do not prevent death, and may deny the person's opportunities to be with their loved ones and share this important time of a person's life. This trend has been noted for several decades and is felt to be due to the medicalization of the dying process when intervening becomes futile and counterproductive.

At times this resistance to a patient's wishes is framed in a strong, authoritative, even threatening tone. There may be threats of nonpayment from insurance, or of not supporting ongoing and essential needs for comfort care if the choice taken is against the medical care giver's advice. Insurance companies have not stopped payments in these circumstances, however, and health care providers may not simply abandon their patients. You will need to be clear, firm, and assertive about your decisions. Your choices, while stated in a convincing form, can still be framed with gratitude for the concern the health care providers have shown, and let them know you are not refusing further palliative or other support from them as it becomes necessary.

Other choices that will be discussed in this chapter include hospice care, palliative care, terminal sedation, and patient-controlled death.

## **Hospice**

Hospice is a medical service that specializes in providing care for the dying. Hospice care focuses on the palliation of a terminally or seriously ill person's pain and discomfort. This includes physical symptoms and emotional and spiritual needs. Hospice care also involves assisting the patients' family members. They help them provide the care and support needed to keep the patient at home and help them cope with the difficulties of a loved one nearing death. Assistance in

bathing, feeding, skin care, and other daily needs can be provided. Bereavement support is also part of Hospice care, so family members are supported even after their loved one dies. There are also some inpatient hospital facilities that provide hospice care. Hospice care is usually instituted when there is an acceptance that the end of life is near and that aggressive curative treatments are not being considered. When a person reaches the point that additional medical treatments are counterproductive, hospice can offer the hope of a comfortable and dignified death.

In the United States, Medicare, Medicaid, and other health insurance providers cover care by hospice providers when the patient has a medical condition with a terminal prognosis diagnosed by a physician who certifies that their life expectancy is less than 6 months. Once hospice care is instituted, it can continue indefinitely until the patient dies (even if the person lives more than 6 months). Sometimes a person recovers and “graduates” out of hospice. It can always be reinstated in the future. This saves money because curative procedures including emergency room visits and hospitalizations are avoided. This, in turn, avoids the emotional trauma of unnecessary medical interventions and trips to health care facilities. The Medicare hospice benefits include pharmaceuticals and supplies, medical equipment, 24-hour access to care, and support for loved ones following a death.



Historically, “hospitality” for the ill and dying, particularly for the poor was provided by religious organizations. This was for the care of persons with illnesses for which no cure was available such as Tuberculosis. The attention included the basic needs such as room and board, help in daily living activities, as well as spiritual and emotional support. The growth of the hospice movement in the last century, starting with volunteers and religious orders providing services has grown internationally. It is now an established medical specialty with physicians, nurses, social workers and other trained personnel providing the services.

Each year, more than 1.5 million Americans receive hospice services. It is common for hospice care to be requested very late, often in the last few days of life. 35% of people who have hospice care don't even receive one week of the service. People nearing the end of life and their families express great appreciation for the care of hospice and commonly state they should have instituted this much earlier. It can be difficult to admit that an individual's disease has progressed so much that additional treatment is impractical and ineffective, but caregivers and their families can lose out on irrecoverable time with a dying loved one if they wait too long to seek hospice care.

## **Palliative Care**

Palliative care is a medical specialty that focuses on providing relief of symptoms such as pain and other discomforts, as well as the stress of a serious illness.

These specialists have no intention to seek a cure. The goal is to improve the quality of life for both the patient and their family. Palliative care teams are made up of doctors, nurses, and other professional medical caregivers, often initiated at the facility where a patient will have first received treatment for their illness. These professionals will administer or oversee most of the ongoing comfort care patients receive. Palliative care teams make an effort to learn what the individual wishes and prefers. They develop relationships with the patients and their families and urge them to participate in making health care decisions.

Hospice care and palliative care are very similar when it comes to the most important issue for dying people, *care*. Many people have heard of hospice care and have a general idea of what services hospice provides. What they don't know or what may become confusing is that hospice provides "palliative care".

Palliative care is both a method of administering "comfort" care and increasingly, uses established protocols to relieve pain and discomfort offered commonly by hospitals. As adjuncts or supplements to some of the more "traditional" care options, both hospice and palliative care protocols offer a combined approach where medications, day-to-day care, equipment, bereavement counseling, and symptom treatment are administered through a single program. Where palliative care programs and hospice care programs differ is in the location, timing, payment, and eligibility for services.

While palliative care can be administered in the home, it is most common to receive palliative care in an institution such as a hospital, extended care facility,

or nursing home that supports palliative care teams. There are no time restrictions. Palliative care can be received by patients at any time and at any stage of illness whether it is terminal or not.

Since this service will generally be initiated through a hospital or regular medical provider, it will likely be covered by regular medical insurance. Since there are no time limits on when you can receive palliative care, it acts to fill the gap for patients who want and need comfort at any time during their illness, regardless if the onset was recent, or a chronic or terminal disease. With palliative care, there is no expectation that life-prolonging therapies will be avoided. It is appropriate for patients of any age and at any stage of a serious illness. It can be provided along with curative treatment. The palliative care team may work together with a patient's other doctors to provide that extra layer of support.

There are studies that have examined the quality of care at the end of life. Family assessments of the quality of care were significantly higher when patients had palliative care consultations during the last weeks or months of their lives. The highest reported quality of care was when patients had palliative or hospice care.

## **Terminal Sedation**

There is much interest in the maintenance of dignity during the final days or hours of a person's life. It is common for people to express the desire to have

some control over how and when they will die. Some people even request help in dying, and there are political movements towards empowering individuals to make these decisions. The states of Oregon, Washington, Vermont, and California have passed so-called "Death with Dignity" laws which set up a strictly regulated method of speeding one's death. An individual who is in the last six months of life as verified by physicians, and who is not mentally ill, can request and receive medications that will cause their death. Montana's Supreme Court decided that individuals in Montana have the right decide to hasten their death in particular situations. In Oregon, where the law has been in effect since 1997, from 40 to 50 persons speed their deaths each year by taking the lethal prescription. Similar laws exist in Holland, Belgium, Switzerland, Luxemburg, and now in Canada.

Dr. Jack Kevorkian publicly championed a terminally ill patient's right to die via euthanasia and claims to have assisted over 120 patients to that end. Because of his videotaped and publicized activities in assisting patients to die outside the context of legal safeguards, he was sentenced to prison for second-degree murder in 1999. The controversial actions of Kevorkian, as well as the "Death with Dignity" laws and the controversies around the ethics of assisting patients to die, have increased the interest in having strategies that ease discomfort in the final moments of life, but are not aimed at speeding death. This has led to substantial improvements in palliative care.

According to the Council on Ethical and Judicial Affairs of the American Medical Association (AMA), it is unethical to hasten death or to help patients die. It is also illegal to administer medications with the purpose of helping a person to die outside a specific legal protocol where it exists. In most states, there is no legal method to provide a patient with a method to commit suicide, so this option is not one that you can reasonably request under the principle of autonomy, except in those states with the legal protocols for this. Even in states with existing “Death with Dignity” laws, not all doctors will agree to offer such services in agreement with those influential organizations that express ethical concerns.

**Terminal sedation** (also known as **palliative** sedation) is the practice of giving a patient sedative medication that will induce sleep or unconsciousness until such time as death occurs as a result of the underlying illness or disease. Usually, the sedative is given by intravenous or subcutaneous injection. This is considered as a last resort when there is an insufficient response to medications that would otherwise ease suffering. There is the risk of a “double effect” of terminal sedation. Although the intention is to relieve suffering, administering the sedatives may contribute to an earlier death.

An example of this may be seen in the following story. Darcy had metastatic cancer of his salivary gland. His tumors were growing in his throat and neck affecting his ability to breathe and swallow. They were not responding to any treatments to slow their growth, and he was experiencing increasing levels of

pain and shortness of breath. He was under the care of a hospice program with the aim of making him as comfortable and as alert as possible during the remaining days of his life. He made it clear that he wanted the pain to be controlled even if it meant sacrificing alertness.

On the last day of his life, after having breakfast with his family, he began experiencing increasing and unbearable pain. The hospice nurse during her regular visit that day talked privately with him about the loss of awareness that would come if his pain were to be relieved with additional medications, and that he would probably never regain awareness. He accepted this eventuality. He met with each of his family members present to say goodbye, then the medication was administered. He died peacefully 12 hours later, with his family by his side.

In 2008, the AMA's council on Ethical and Judicial Affairs approved as ethical the practice of palliative sedation. This practice is now legal in the United States and in many European countries (it is not legal in some countries) under legal safeguards that include counseling and informed consent. It makes it easier for the patient to die in comfort and dignity, knowing that relief will be available. It does not causally contribute to death. It constitutes help *in dying* and not help *to die*.

Considering the possibility of being in severe distress during the final period of life, it is important that you make clear your wishes for the relief of suffering even if it sacrifices your alertness. This can be done with your health care providers, with hospice personnel if they are involved in this final period of your life, and with the person you have chosen in your Durable Power of Attorney for Health Care (chapter 9).

### **Patient Controlled Death**

Another end-of-life option that is gaining social acceptance is the choice of when to die. This means that a competent adult with a severe and incurable condition without prospect for improvement can request assistance in causing their death. This assistance may be from a physician and/or from other intimate individuals who can provide the support to carry out the process necessary to end a life.

In 2014 Brittany Maynard, a 29-year-old Californian, was diagnosed with terminal brain cancer. Rather than let the illness take its dreadful course she moved to Oregon where the “Death with Dignity” law exempts doctors from prosecution if, when following the legal safeguards, they prescribe life-ending drugs to terminally ill patients who request them. She chose the date of her death at a time before she was incapable of taking the medications on her own and when she was certain her remaining days would be filled with pain and suffering. The publicity of her case increased awareness of this option. California subsequently

created a legal process for residents of that state to obtain medications for the purpose of ending their life.

As noted, physician-assisted death is legal in 5 U.S. states, and there are proposed laws to legalize this in many other states. These laws require a patient to have a medical condition, certified by two physicians that give them less than six months left to live. The person must be legally competent (i.e. not be mentally ill) to make the decision. They must be a resident of the state and be capable of self-administering the medication that will cause their death.

Oregon, by passing a “Death with Dignity” ballot proposal in 1994, was the first state that established a legal process to allow a physician to prescribe a lethal dose of a medication that a patient must self-administer. In the first 18 years that this has been allowed (the practice was allowed in 1997 since court deliberations delayed the onset of the law), approximately 1000 people have been helped to die through this legal process. It should be noted that when a person invokes the “death with dignity” laws and proceeds through the legal safeguards to take the medications that will cause their death, the law states that this is not to be considered suicide. (While suicide is not illegal, anyone assisting someone to commit suicide is committing a felony.)



Historically, many doctors have quietly eased terminal agonies by increasing pain relief to life-shortening doses. Under the *doctrine of double effect*, as long as the intention was to relieve suffering rather than hasten death, doctors were rarely considered to have committed a criminal or ethical malfeasance. Physician-assisted death is deemed unethical by the British and American Medical Associations, however. “Nor shall any man’s entreaty prevail upon me to administer poison to anyone; neither will I counsel any man to do so,” runs the Hippocratic Oath, written nearly 2,500 years ago. Recently the California Medical Association has moved towards a more neutral stance where legal safeguards are provided by “Death with Dignity” laws.

Some European nations have laws permitting physician-assisted death for competent citizens of their nations who request it. In the Netherlands, Belgium, and Luxemburg the patient must be certified by a physician to have a condition that causes unbearable suffering without prospect for improvement. The individual requesting the assistance does not have to be certified as having a terminal condition. Patients do not need to self-administer the lethal medications in these countries, as physicians may give the medications by injection.

Switzerland has the most lenient laws. It has been legal there to assist people in dying since 1942, and the individuals do not have to be Swiss citizens. The law states that assisted death is punishable only when it is done for “selfish” reasons. There are assisted dying clinics specializing in providing the services. A large

clinic, *Dignitas*, has developed a reputation for “suicide tourism”, since they accept foreigners. More than 1,700 people from more than 40 different countries have traveled to Switzerland and ended their lives there since 1998.

Anyone considering planning their death should have counseling, palliative care, and hospice services readily available. The fears that having legally approved structures for planning a death would undermine the development of end-of-life support services have not been realized. In fact, since Oregon and Washington have passed their “Death with Dignity” laws, there has been a substantial increase in hospice and palliative care services. Care at the end of life has improved for all people, including those who choose to control their death under the laws, and those who do not.

Travel to another state or country in order to have legally approved assistance for a patient controlled death may not be possible or may be impractical and difficult. Brittany Maynard, for example, had to move to Oregon and live there for 6 months in order to establish residency before she could invoke the “Death with Dignity” law. The inability to travel may force a person to take their life early if they have to do it themselves, without medical assistance. This is one of the reasons that laws have been passed. They allow people to delay their deaths knowing they will have the legal structure and support to make a decision later. However, other options do exist for adults, competent to make their own decisions, who have an irremediable and grievous condition.

## **Voluntarily Stopping Eating and Drinking (VSED)**

Stopping all nutritional and fluid intakes—complete fasting—will cause death, usually within one to three weeks depending on an individual's underlying condition. It is legal to cause your own death by so doing. Dehydration is the ultimate cause of death. This method of accelerating dying has been recognized and accepted for a long time. There are many well-publicized reports of individuals with terminal conditions and non-mortal conditions that will lead to a reduced quality of life, who have chosen to hasten their deaths by VSED. People with early dementia have made this choice before they lost the competence to do so, and there are several publicized cases (described in the Journal of the American Medical Association and the New York Times) of elderly people who were "tired of living" who made the decision to stop eating and drinking.

Since VSED is a natural process of dying, people experience a range of symptoms as the dehydration progresses. Most individuals who hasten their death by this approach die peacefully and with dignity according to hospice nurses. An individual who chooses this process will gradually become weaker and have little energy. Some people describe a sense of peace, even euphoria. Others become confused and agitated. Mental alertness recedes and people become very sleepy after the first few days. Most people go in and out of

consciousness. The dehydration frequently causes the mouth to dry out and the lips to be parched and cracked, the tongue to swell. There may be nose bleeds. Nausea, vomiting, and abdominal cramps may develop. After several days there may be confusion and agitation. Rarely there are convulsions.

For a VSED death not to be painful and uncomfortable, individuals need medical and other caregivers to support them during the dehydration process. The person may need help because of weakness and light headedness. Medications used to manage pain may need to be continued. Sedatives for anxiety and agitation may be needed, as well as personal help with local discomforts such as moisture for the lips and mouth. 24-hour support will be necessary. Supporters must understand how the fast may progress, and not provide any fluids for this to proceed without actually prolonging the patient's discomfort.

In conclusion, when a person considers a patient controlled death, talking with their family and care providers is important. They need to be aware of her end-of-life wishes, values, and concerns. She can describe to them her suffering and fears about further deterioration of her quality of life. Hospice will usually support these conversations. A consultation with a mental health provider addressing depression and decision making capacity is frequently recommended.

There are organizations that can provide information and consultation about a patient controlled death. **Compassion & Choices** offers such help. They are well experienced and recognized for their support of end-of-life choices, and have built a reputation for their work in this area. They offer an *End of Life Consultation* program. Their U.S. phone number is 800-247-7421 and their web site is [www.compassionandchoices.org](http://www.compassionandchoices.org) .