STOPPING EATING AND DRINKING

This is one option for ‘decisionally capable’ adults who wish to hasten dying. What are the ethical and legal implications for nurses?

OVERVIEW: Voluntarily stopping eating and drinking, in which death occurs within one to three weeks of beginning the fast, is increasingly explored in the literature and mainstream media as an option to be discussed with “decisionally capable,” suffering patients who want to hasten their dying. The author uses an example from her experience to describe stopping eating and drinking, as well as other clinical practices associated with hastening dying; explores whether this practice can or should be distinguished from suicide; and discusses the ethical and legal implications for nurses.

Gertrude (not her real name; other identifying details have been changed) was 99 years old. Having survived the Holocaust and overcome many other challenges in her long life, she thought it ironic that she had to ask her children to help her die.

Although she was not terminally ill, the quality of her life was significantly diminished by many chronic ailments. Despite two hearing aids, her hearing loss was such that she could no longer indulge her one remaining pleasure: listening to classical music. She had fallen and broken a hip when she was 96 and now had to use a wheelchair when moving around her apartment. She had severe arthritis, and she

The Last Best Option?

I first met Gertrude and her two adult children, Adam and Susan (all names and other identifying details have been changed) in Gertrude’s apartment. The live-in housekeeper who cared for Gertrude was away for the afternoon. Gertrude told me she wanted to die—
terminal diagnosis qualify under a category called “debility and decline.”

As her shingles-related pain gradually subsided, Gertrude developed a warm relationship with Rose, her hospice nurse; Rose’s weekly visits became a high point in her week. Gertrude felt comfortable asking Rose for advice about how she could end her life. Rose told Gertrude she couldn’t help her die and referred her and her children to the nonprofit end-of-life advocacy and consultative organization where I work. I gave Gertrude and her children information about the few legal end-of-life options that might hasten dying for someone who’s not terminally ill or in the last days of life, such as stopping life-sustaining medications and stopping eating and drinking. (For more on common clinical practices that hasten dying in patients who are terminally ill and in the last days of life, see Clinical Practices that Hasten Dying.1-14) After several meetings and much discussion about the benefits and burdens of these options, Gertrude elected to stop eating and drinking. She died peacefully 10 days after she began her fast. Her family gave me permission to tell her story. (For a more detailed account of my experience with Gertrude, see The Last Best Option?)

BACKGROUND

The diseases and conditions that most frequently cause death in the United States—cardiovascular disease, including congestive heart failure and stroke; chronic lower respiratory diseases; cancer; diabetes; and dementia—are often associated with periods of prolonged disability and suffering before death. For patients with these conditions, a “good death” is often an unrealized goal.

rarely left her apartment except for medical appointments. All friends and many family members had long since died, and her deteriorating vision—a result of a recent bout of shingles—left her unable to read or watch television. After years of living with these and other chronic conditions, she told her family she was tired of life and was ready to leave. Her children and grandchildren told her to be patient. She was almost 100; surely she would soon die peacefully in her sleep.

The tone and frequency of her requests for help in dying changed dramatically after her ophthalmologist told her she would never regain her vision. She had held out hope that her vision loss was temporary, and now she said she could no longer tolerate life without sight. Although stoic by nature, Gertrude had experienced such intense pain from shingles that her primary care physician had felt ill-equipped to manage it and had recommended she receive home hospice care for the purposes of pain management. (Although patients typically qualify for hospice care only if they have a terminal illness with a prognosis of six months or less to live, some patients in progressive decline but without a}

disappointed when I told her that such a pill didn’t exist and that, even if it did, I wouldn’t administer a lethal drug to her. She wasn’t the least bit interested in hearing about the procedures and guidelines of Compassion and Choices, the advocacy organization I work for, or in the legal and ethical distinctions among such acts as killing, letting die, or presenting options for intentionally hastening dying.

I asked Gertrude to tell me about her life and why she wanted to “go to sleep and never wake

PALLIATIVE CARE

Palliative care provides symptom relief and the best possible quality of life not just for dying patients but also for those with a life-threatening or incurable and progressive disease. Ideally care begins at the time of diagnosis and may accompany treatments aimed at curing the disease or slowing its progress. Hospice is palliative care for terminally ill patients in the last six months or less of life who are no longer seeking treatment to cure their condition. This care is entirely focused on relieving symptoms rather than curing illness.

Palliative care should be the standard of care for all dying patients, but too often it’s not. Despite efforts to integrate palliative care into mainstream disease management, many dying patients as well as those with progressive chronic illness receive inadequate relief from pain and suffering.
Anecdotal evidence and my own experience suggest that a growing number of frail, elderly people with multiple chronic illnesses who are able to make decisions are seeking ways to achieve, to quote a recent New York Times article, a “graceful exit” from a life that, as they see it, has simply gone on too long.14 Inevitably, a small proportion of these suffering, dying patients will ask their nurses for help in dying in order to escape their suffering.2, 10, 16

WHAT NURSES SHOULD KNOW

The decision to voluntarily stop eating and drinking differs from the loss of appetite or disinterest in food or drink that often accompanies the final stage of many illnesses. In this case, the patient is physically able to eat and drink but chooses not to; the intention is to hasten dying.

Depending on the patient’s physical condition, death usually occurs within one to three weeks of beginning a fast. The process requires a well-informed and determined patient who has family, friends, or others who can provide emotional and physical support; it’s also crucial that the patient have access to clinical caregivers who can provide palliative or hospice support. Patients and their loved ones who consider this option must understand in particular the importance of stopping all fluids (including ice chips) once the fast has begun so that death occurs within the one-to-three-week interval.

Once oral intake stops, the patient usually remains wakeful and responsive for several days while weakening physically. This interval allows the patient to reflect on and perhaps reconsider the decision—and for loved ones to reminisce and prepare to say goodbye. Family members and other caregivers must be prepared for the possibility that the patient may decide to eat and drink again and support any decision the patient makes. If the patient wishes to resume eating or drinking, caregivers must provide food and fluids.

Also important is excellent oral care, particularly during the initial stage of the fast, when the patient is conscious and may be thirsty or have a dry mouth; using oral swabs and lip salve, rinsing the mouth and having the patient spit out fluids, or misting the back of the mouth with mouthwash or another fluid will help keep the mucous membranes moist and lessen discomfort. As dehydration progresses, the patient will become sleepier, eventually slipping into a coma before dying. Excellent physical care should continue, and loved ones may find comfort in providing it.

Occasionally, delirium or agitation may occur as death nears. Caregivers should be prepared for this possibility and know to contact a hospice nurse or palliative care clinician to provide palliative measures, including sedation, to ensure a peaceful death. When asked what it’s like to care for hospice patients who voluntarily stop eating and drinking, nurses in one study said that this choice doesn’t seem to cause unacceptable discomfort or distress and appears, in most cases, to facilitate a peaceful or “good” death.17

ETHICAL AND LEGAL CONSIDERATIONS

All patients who request information about hastening dying must be assessed by a clinician who seeks to understand the meaning of the request, the underlying physical or psychosocial reasons for it, and the patient’s decision-making ability. When a patient asks a nurse about options to hasten dying, other members of the health care team should be informed of it. It’s particularly important that mental health specialists skilled in assessing decision-making capability be consulted when patients who are not terminally ill ask about stopping eating and drinking; depression, for example, can be difficult to recognize in a frail older adult.

Many palliative care clinicians agree with ethicists who view stopping eating and drinking as a form of forgoing life-sustaining treatments that’s consistent with the ethical and legal consensus supporting a competent patient’s right to refuse interventions. They note that not honoring a competent patient’s refusal of food and drink can lead to forcing treatment on an unwilling patient: tube feedings that require the use of physical restraints and which violate the patient’s autonomy, dignity, and liberty.18

up.” In a coherent and resolved manner, she described how circumscribed her life had become and how confined she felt by her dimming vision and loss of hearing and other limiting physical conditions. She’d lived a wonderful life and had accomplished much, and now she had no interest in just existing. She particularly missed being able to listen to classical music. Despite the presence of her caring and attentive family, she was no longer able to do any of the things that had once made life enjoyable and meaningful.

I asked her what medications she was taking; in certain instances, stopping life-prolonging medications can lead to a peaceful death. In Gertrude’s case, that wasn’t feasible. I then briefly described the option of stopping eating and drinking. I asked her whether she continued to enjoy eating—was this perhaps a remaining source of pleasure? She assured me that she had no appetite at all and only ate to please her housekeeper. She was appalled, though, when I told

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A number of clinical practices associated with hastening dying occur routinely in health care settings across the country. These practices include

- forgoing or discontinuing life-sustaining treatment, including medically provided nutrition and hydration (such as tube feeding).
- using high doses of opioid analgesia.
- initiating palliative sedation.
- physician-assisted dying (legal only in Oregon and Washington State; a ruling permitting it is being appealed in Montana).

Forgoing or discontinuing life-sustaining therapies is a well-accepted right of all patients and is implicated in as many as 84% of hospital deaths in the United States. Although there is no recognized moral or legal distinction between withholding or withdrawing life-sustaining treatments, some clinicians find the withdrawal of life-sustaining measures to be more troubling than the decision not to initiate such treatments. Some nurses may fear being held responsible for the death of a patient after the withdrawal of life-sustaining measures. But such fears are without legal or ethical foundation because it is the patient’s decision to forgo interventions.

Patients still able to make decisions (or the surrogates of those who’ve lost decisional capability) have a right to make informed treatment decisions that reflect their personal values and wishes (or in the case of a surrogate, the patient’s values and wishes), and nurses have a corresponding duty to respect and support those decisions. This means that patients have a right to refuse unwanted treatments regardless of the nature of the treatments, the status of their disease, or the reason for their refusal (including the desire to hasten or cause their own death). Decisional capacity should be understood as the ability to receive and understand information about choices, evaluate the choices without external influence or coercion, and communicate a decision and the reasoning behind it.

Withholding or withdrawing life-sustaining interventions allows the patient to die of her or his illness and is distinguished from illegal or ethically unjustified killing or “assisted suicide” by the informed consent given to the clinician by the patient or the surrogate. Nurses who support a patient’s decision to forgo life-sustaining treatments can be assured that they are acting appropriately.

Providing high-dose opioids at the risk of hastening dying. All nurses must be able to manage symptoms in any patient in pain, regardless of the clinical setting, the patient’s age, or the nature of the disease. This is especially true in patients who are actively dying. Yet many nurses, particularly those inexperienced or untrained in palliative care, may be concerned about hastening dying through the use of opioids and may be reluctant to administer the often-necessary high doses. Even experienced hospice and palliative care nurses sometimes question their own actions and motivations when a suffering patient dies shortly after receiving an appropriately titrated opioid dose.

But according to the Hospice and Palliative Nurses Association (HPNA) position statement Providing Opioids at the End of Life, “[T]here is no convincing scientific evidence that administering opioids, even in very high doses, accelerates death. . . . Respiratory depression and other changes in breathing are part of the dying process and are more likely to be from disease and multi-system organ failure than from opioids.”

Many clinical guidelines offer support for opioid use by appealing to the “rule of double effect.” This rule can be invoked to justify an intervention that aims to achieve a positive outcome (pain relief) while acknowledging the possibility of

her that the process of dying by forgoing food and drink might take up to three weeks. That was too long, she said. We spoke for about an hour. As I got ready to leave I could see that Gertrude was tired and disappointed. She hadn’t heard what she’d hoped to hear. I agreed to meet again if Gertrude wished to do so, and invited them to call me if questions arose.

Susan had told me that Gertrude’s 100th birthday was soon to arrive. Susan’s daughter, who lived out of town, was coming and they were going to have a big party. Gertrude had partially raised this granddaughter, and they were very close; she hadn’t yet told her of her wish to hasten her dying. Gertrude wasn’t interested in a party, but she understood how important it was to her family and so she accepted the flowers, balloons, and cake.

At Gertrude’s request, I visited her again two and a half weeks after the first visit. Susan told me that at the birthday celebration Gertrude had told her granddaughter that she wanted to die. Her granddaughter had gradually and tearfully come to understand—if not entirely to accept—her grandmother’s wish.
a negative outcome (hastened dying). This rule challenges clinicians to explore their intentions and clinical goals when treating suffering patients and is often cited to explain why one end-of-life intervention that results in death is morally and legally acceptable while another with the same result but with a different intention is not. According to the American Nurses Association’s Code of Ethics for Nurses with Interpretive Statements, “The nurse should provide interventions to relieve pain and other symptoms in the dying patient even when those interventions entail risks of hastening death. However, nurses may not act with the sole intent of ending a patient’s life...”

Initiation of palliative sedation. A decision to initiate what is often called “palliative,” “total,” or “terminal” sedation is understood to be a last-resort intervention to relieve intractable suffering in a dying patient when other palliative efforts have failed. The clinical goal of this intervention is not to hasten or cause death but to render the patient unconscious so that she or he is unaware of symptoms. A patient or surrogate decision maker must provide informed consent. Sedation is generally induced by subcutaneous or intravenous infusion of benzodiazepines, and the rate of infusion is titrated to maintain a continuous sleep-like state. Opiate medications continue to be administered to provide pain relief.

The following clinical conditions are usually present: the patient has unendurable symptoms that are refractory to the standard means of palliation and is near death if not imminently dying. A conference with the patient, family members, and members of the palliative care team is arranged to discuss the option of palliative sedation and to clarify its goals, risks, and benefits. Once the option is agreed upon, the patient or surrogate can decide whether to continue other life-prolonging interventions like nutrition and hydration, which are often clinically warranted and overly burdensome to the dying patient.

When speaking of the inappropriate use of morphine drips to intentionally hasten dying, clinicians have used the term “slow euthanasia.” Such condemnation is justified when the infusion rate of the sedating drugs is inappropriately and continually increased, without being adjusted to the patient’s symptoms or response, until respiratory depression leads to death. But palliative care experts who view their duty to relieve suffering as a moral imperative argue persuasively that palliative sedation, when appropriately employed, is an important option that’s morally and clinically distinct from any form of euthanasia.

Euthanasia is defined as the administration of drugs with the intention of ending a patient’s life at the patient’s request. Although it’s illegal in all states, it nonetheless occurs across the country as part of the underground and unregulated practice of clinician-aided dying. Because both palliative sedation and euthanasia have the same outcome (the patient’s death), if the patient or surrogate is not actively involved in the decision to initiate sedation, clinicians may risk later challenges to their clinical judgment about the refractory nature of the symptoms or their intention in providing the sedation. To avoid such concerns, clinicians should carefully document the patient’s clinical history, all palliative initiatives employed, and the process of obtaining informed consent. All members of the health care team must be informed about the clinical justification for use of this palliative measure.

Physician-assisted dying. The majority of Americans who wish to control the circumstances and timing of their death cannot legally obtain a physician’s assistance in dying. Oregon was, until last year, the only state to pass a law that permits “decisionally capable,” terminally ill people to receive a prescription for a lethal amount of medication from a physician. (Washington passed a law similar to Oregon’s in 2008. Montana has no such legislation, but in December 2008 a Montana judge ruled that

Gertrude told me that in the time since our first meeting she’d come to accept that stopping eating and drinking was the only way she could legally control the circumstances and, to a degree, the timing of her death. Rose, the hospice nurse, and Susan were present at the second meeting. I described each step of the process. Arrangements had to be made before Gertrude’s chosen date to begin her fast. Even though Susan intended to move back to her mother’s apartment to oversee her final days, the family would have to hire two competent nurses’ aides to keep Gertrude clean and cared
Physician-assisted dying was permitted under Montana’s constitution; the ruling is currently under appeal.) In Oregon and Washington, a licensed physician can write a prescription for a lethal amount of medication after

- a 15-day waiting period separates two verbal requests and one written one.
- the physician determines that the patient is terminally ill, is “decisionally capable,” is making a voluntary and informed request, and has received information about access to hospice or comfort care; a second physician must confirm and document the diagnosis, prognosis, and the absence of any decision-impairing mental or cognitive disease.11

This social experiment in physician-assisted dying has been ongoing in Oregon for almost 12 years and has yielded valuable information on what can happen when a practice that was illegal, unregulated, undocumented, and underground becomes open, regulated, and publicly documented. The fears about physician-assisted dying leading to involuntary euthanasia turned out to be unfounded. An unexpected outcome of this legislation is how infrequently it’s used; another is the dramatic increase in the use of hospice care by the terminally ill. From 1998 to 2008, 401 patients have died using the law.12

There is no “typical” patient who self-administers lethal medication, but thus far the majority are white, college educated, enrolled in hospice, insured, suffering from cancer, and not suffering from inadequately managed pain.12

In October 2006 the Oregon Department of Human Services adopted a policy to cease using the term “physician-assisted suicide” when referring to those who take advantage of the Oregon Death with Dignity Act, a position consistent with the language of the law, which states that actions taken in accordance with the act do not constitute suicide or assisted suicide. And in 2007 the American Academy of Hospice and Palliative Medicine (AAHPM) published a position statement explaining its reasons for preferring the term “physician-assisted death,” stating that it more accurately describes the process than “the more emotionally charged designation physician-assisted suicide.”13 The AAHPM also took a position of “studied neutrality” on the question of whether physician-assisted dying should be legally regulated or prohibited. In 2006 the HPNA reiterated its opposition to the legalization of “assisted suicide.”14

Outside of Oregon and Washington State, clinician-assisted dying, including active euthanasia, exists as an ongoing but secret practice without oversight or publicly agreed-upon safeguards to ensure that vulnerable patients provide informed consent, have access to appropriate pain management and hospice care, and make an enduring and voluntary request for assistance in dying. Surveys of non-Oregon nurses have reported that approximately 3% of respondents acknowledge intentionally providing patients with lethal injections “without specific request.”10

Although few legal cases specifically address a competent person’s choice to stop eating and drinking, in two New York lower court cases nursing home administrators sought legal authorization to compel the use of feeding tubes in two elderly women who refused oral intake.19 The judges in these cases refused to intervene, despite the nursing homes’ appeal to a New York statute “authorizing prevention of suicide.”

For as she became increasingly weak and then bed bound, Susan began to interview prospective aides, several of whom Rose had recommended. It was important that the aides be able to support Gertrude’s end-of-life wishes. Gertrude’s housekeeper, who had worked for her for many years, informed Gertrude and Susan that her beliefs as a devout Catholic rendered her incapable of supporting such wishes.

We also discussed what to do if Gertrude changed her mind and asked for something to drink or eat. Although Gertrude assured everyone that such a thing wouldn’t happen, I described to Susan and Rose an appropriate way to respond in the event that it did. Sometimes patients forget they have made a decision to stop all oral intake—a consequence of early dementia or because of an electrolyte imbalance that causes confusion. Caregivers should gently remind the patient of the previously made decision to stop eating and drinking and of the patient’s wish to hasten dying in this manner. If, after a reminder, the patient still requests food or fluid, caregivers should promptly comply with the request. (Rose acknowledged that...
a patient information about stopping eating and drinking.\textsuperscript{20}

Nurses are not required to participate in clinical practices that offend strongly held values or beliefs, yet they ought not impose their personal values on patients if doing so limits patients’ access to information about legal end-of-life options. There’s growing support for the idea that clinicians who believe it’s morally unacceptable to talk to a patient about voluntarily stopping eating and drinking should transfer care to another clinician who will provide information on all legal options.

**ETHICAL AND LEGAL VIEWS OF SUICIDE**

Most people believe they know what suicide is, but the word can be defined in different ways. Some courts describe suicide as the self-infliction of deadly harm with a specific intent to bring about death, or “wrongful self-killing.” Although suicide (attempted or committed) was once considered a felony, it’s no longer illegal in any state. But assisting in a suicide is illegal in all states except Oregon and Washington. Most but not all states have laws specifically prohibiting assisted suicide, and a number of states have made unsuccessful attempts to pass laws permitting “aid in dying.” Although all states have an interest in protecting citizens’ lives and preventing suicide, a patient’s right to self-determination by forgoing life-sustaining treatment consistently trumps those state interests, even when the patient’s decision to forgo treatment is intended to cause her or his death.

When bioethicists discuss suicide, they begin by using morally neutral language to define the concept, such as “intentional self-killing.” Here the term “killing” does not imply wrongful behavior, and some acts of intentional killing can be seen as both morally and legally justified: self-defense, for example. One ethicist notes that “some self-killings also could be construed as justifiable—as acts of self-defense against intolerable life circumstances or irremediable suffering.”\textsuperscript{21} Another writes that,

> It is a mistake to define suicide as self-inflicted death. Death is not always a harm to the one who dies. To describe death as “inflicted” implies its badness or harmfulness. . . . Common sense supports thinking that dying too late can be a harm just as dying too soon can be. If so, death can benefit the one who dies. When death is the least-bad thing that can happen to a person, and nothing better can happen to him, it benefits him.\textsuperscript{21}

All agree that a critical factor in determining whether to support a patient’s decision to hasten dying is whether the patient is “decisionally capable” and is making a “rational” choice. And some mental health experts recognize that chronically or terminally ill patients who seek to die as a means to escape further suffering are being “entirely reasonable. . . . [S]uch decisions can be reached through rational thought processes and do not necessarily reflect pathological depression or classic suicidal ideation.”\textsuperscript{23}

**THE EXPERIENCE OF STOPPING EATING AND DRINKING**

Patients and their loved ones have increasingly been speaking publically about what it’s like to decide to stop eating and drinking. In 1994 a physician writing in *JAMA* described his mother’s decision to stop eating and drinking after a series of chronic ailments. Eighty-four years old and not terminally ill, she died peacefully of dehydration in a nursing home with comfort care provided by her physician.\textsuperscript{24} Another physician in Oregon described his reaction when an elderly patient who’d grown increasingly debilitated by severe arthritis pain chose to stop all oral intake. He said he watched, surprised, as his suffering patient became self-confident and seemingly happy. Her family gathered. . . . Then, without requesting any palliative care—even ice chips—her body rapidly failed, and she died.\textsuperscript{25}

As he approached death, Michael Miller, a retired surgeon, contacted a journalist and requested that she was relieved to hear this strategy.)

I also advised giving small doses of analgesia by transdermal patch rather than by mouth. Although Gertrude had previously been reluctant to take pain medication for her severe arthritis because she felt it made her too sleepy, she now told Rose that she’d take the medication once she began to fast. After all, she said, she no longer cared if she became sleepy. We agreed that a hospital bed would keep Gertrude safe and make her care easier.
she document his dying by dehydration in a video. Miller knew that his death from cancer was inevitable; he rejected both assisted suicide and euthanasia, electing instead to stop eating and drinking. The filmmaker described Miller’s sense that he’d regained control over his death: “Michael felt he was avoiding a wretched ending. For him, being a surgeon and used to being in control, his view of a wretched ending was about not having influence over how he leaves. For him not eating and drinking was about making the dying process gentler and having some control.”

What these descriptions share with Gertrude’s story is an absence of impulsivity, nervousness, guilt, depression, or any other emotional state traditionally associated with suicidal behavior. Family or friends of people who’ve surreptitiously planned and completed an act of suicide are frequently left with unresolved feelings of shock, guilt, and anger at an act they may perceive as selfish or thoughtless. These sentiments are absent from the descriptions of those present when a loved one chose to stop eating and drinking in order to hasten dying.

**Individual nurses must decide** how they’ll respond to patients’ requests for information about legal end-of-life options that permit hastened dying. Those nurses who value patient self-determination and informed decision making based on all available legal options will include a description of voluntarily stopping eating and drinking. Others who believe that stopping eating and drinking is morally equivalent to suicide may feel unable to discuss this option with their patients. These nurses are encouraged to transfer care of such patients to colleagues who feel differently.

For more than 24 additional continuing nursing articles related to the topic of palliative care, go to [www.nursingcenter.com/ce](http://www.nursingcenter.com/ce).

**REFERENCES**


Susan interviewed prospective aides; Rose ordered a hospital bed and supplies. Gertrude was impatient to begin. I explained that these preparations were important, and she chose a date that everyone could support. The housekeeper moved out, and Susan moved into the spare bedroom. The new aides were hired and were ready to begin. We met again the day before Gertrude’s fasting date. After I told her that she’d probably be very sleepy after a few days of fasting, and that then she’d slip into a coma from which she wouldn’t awaken, she asked me, “How will I know that I have died?” I couldn’t answer her.

I came back to visit with Susan and her mother on the fourth day of Gertrude’s fast. She was asleep and looked peaceful; her skin was luminous. She received excellent care, and even though she might not have been able to hear, Susan kept classical music playing softly in her room around the clock. Gertrude died, without ever waking again, during the night of day 10.


