

Smith Seminars
Continuing Education Credits
AARC-Approved for 2 CRCE
Caring for the Dying Patient

Objectives

Highlight factors when death is near and after death occurs.

Discuss the use of Hospice Care and legal aspects of disability.

Knowledge of symptom control in the dying patient including pain, dyspnea, anorexia, nausea and vomiting, constipation, pressure ulcers, confusion, depression, stress, and grief.

Become familiar with the legal aspects of Do-Not-Resuscitate (DNR) orders and Advance Directives

The traditional medical approach emphasizes goals such as testing until diagnoses are well-established, correcting all physiologic abnormalities, even asymptomatic ones, and pursuing a cure, even when cure is unlikely and therapy is toxic, invasive, or uncomfortable.

To many of the patients facing a fatal illness, these goals may be less important than avoiding suffering and (with their family and friends) finding comfort and meaningfulness during the experience of dying. Therefore care of the dying patient should be guided by a realistic assessment of the situation and the merits of various interventions in light of the patient's values and wishes.

People's priorities differ, especially when facing death. Some prefer life to be prolonged, even at the cost of pain, marked confusion, or severe respiratory distress. They may cherish every moment of life, regardless of its quality. For others, quality of life is the overarching concern. They may fear pain or confusion more than death and prefer comfort measures and shorter survival to prolonged disability and struggle. However, to say that a patient's care has changed from curative to supportive or from treatment to palliation is an oversimplification of a complex decision process. Most patients need a customized mix of treatment to correct, to prevent, and to mitigate the effects of various illnesses and disabilities.

Some people search for closure and reach out to friends and family to share time and to express love; they complete projects important to their lives; and they tie up loose ends. Often, with appropriate support, people die at a time and in a way that allows them to experience a satisfying close. Other people cannot accept their imminent mortality and avoid such closure.

Effective care for dying patients usually involves a clinical team because no one caregiver is available 24 hours a day and because comprehensive and reliable care requires the skills and perspectives of several disciplines. Palliative care or hospice teams anticipate potential problems and make appropriate arrangements, such as obtaining supplies or opioids in anticipation of a potential emergency. Certain team members can help dying patients who have spiritual needs; such needs should be recognized, acknowledged, and addressed. When death is imminent, an experienced team member can comfort family members and may prevent an inappropriate call to the emergency medical system.

When Death Is Near

The physician and the clinical team should prepare patients and family members for death whenever the patient has a condition likely to worsen and cause death, even if death may be a few years in the future. Preparation includes discussion of the likely course and possible complications. Patients should also be advised when death becomes imminent. A health care practitioner must not assume that patients or family members understand the fatal nature of certain disorders (even metastatic cancer) or that they can recognize from the patient's appearance that death is near. Initial discussions should be honest and sensitive to the language and culture of patients and family members. The physician should not delay full disclosure too long because doing so can provide false hope and distort decision making, for example reducing the opportunity to attend to spiritual and family concerns. Many patients and family members benefit from making plans based on their priorities and preferences for end-of-life treatments.

Many patients ask whether the clinician can predict the time until death. Such estimates are ordinarily incorrect, both for slowly progressive disorders and for disorders in which death tends to come suddenly, without reliable warning signs (such as heart failure or emphysema). For some cancers, recognizable warning signs may presage death by several weeks or months. In contrast, many people live for months or years in an unchanging but very fragile state of health. Clinicians tend to give inaccurately optimistic estimates and often are reluctant to predict life expectancy. Some models, such as predictions of in-hospital mortality for ICU patients using APACHE II, are accurate for groups but not for individuals. If a clinician notes that a patient is sick enough that it would be “no surprise” for the patient to die in the coming year, the patient could die with the next complication, which could develop at any time. In such cases, clinicians, patients, and families should consider prioritizing comfort and life closure over at least the burdensome elements in conventional medical treatment, as well as much of prevention services. Family support, advance care planning, focus on relieving symptoms and maximizing function, and attention to spiritual issues are appropriate for patients who are in such fragile health. Clinicians lose many opportunities to help patients and their families live well and meaningfully by postponing the recognition of fragile health until death is clearly imminent.

At some point, virtually every dying patient should have a do-not-resuscitate (DNR) order or a do-not-attempt-resuscitation (DNAR) order written in the medical record. All clinicians in every setting should abide by that decision. Patients, families, and the clinical team should also make and record other important decisions about medical care including whether patients are to be hospitalized or use a ventilator. Often, implementing these decisions requires specific actions, such as to have the needed drugs at home. Family members should know about the changes that may occur in the patient's body shortly before and after death. They should not be surprised by irregular breathing, cool extremities, confusion, a purplish skin color, or somnolence in the last hours. Some patients close to death develop noisy bronchial congestion or palatal relaxation, commonly known as the death rattle. If this symptom distresses family members, scopolamine or diphenhydramine can dry the patient's secretions and reduce the noise. Also, central nervous system (CNS) irritability, with agitation and restlessness, may develop. If these symptoms, after review, are judged not to be caused by a drug or untreated disorder, then they can be relieved by a sedative.

If a patient is expected to die at home, family members should rehearse whom to call, physician, hospice nurse, clergy, and know whom not to call such as ambulance service or 911. They should also have help in obtaining legal advice and arranging burial or cremation services. Religious practices that may affect after-death care of the body should be discussed before death with the patient, family members, or both.

The last moments of a patient's life can have a lasting effect on family members, friends, and caregivers. The patient should be in an area that is peaceful, quiet, and physically comfortable. Any stains or tubes on the bed should be covered, and odors should be masked. Family members should be encouraged to maintain physical contact, such as holding hands, with the patient. If desired by the patient and family members, the presence of friends and clergy should be encouraged. Accommodation should be made for spiritual, cultural, ethnic, or personal rites of passage desired by the patient and family members.

When resuscitation is attempted, family members often appreciate being present during the resuscitation.

After Death Occurs

A physician, nurse, or other authorized person should pronounce the patient dead in a timely way to reduce the family's anxiety and uncertainty. The physician also should complete the death certificate as soon as possible because funeral directors need a completed death certificate to make final arrangements. Even when death is expected, physicians may need to report the death to the coroner or police; knowledge of local law is important.

Telling family members about death, particularly unexpected death requires effort. The physician should use clear language when informing the family that death has occurred, such as using the word "died". Euphemisms, such as "passed on" should not be used because they are easily misinterpreted. If the family was not present during resuscitation, any events near death, including resuscitative efforts, should be described and the patient's absence of pain and distress mentioned, if true. It is usually wise to be sure that the closest kin is not alone. When told about death, particularly unexpected death, families may be overwhelmed and unable to process information given to them or to formulate questions. Physicians, nurses, and other health care practitioners should respond to the psychological needs of family members and provide appropriate counseling, a comfortable environment where family members can grieve together, and adequate time for them to be with the body. When feasible, it may help for a clinician to be with the family members as they enter the room with a newly dead body, since that situation is so unfamiliar to most people. Sometimes, it is best then to leave family members alone for a while, then return and offer explanations of treatments provided and give the family a chance to ask questions. Friends, neighbors, and clergy may be able to help provide support. Health care practitioners should be sensitive to cultural differences in behavior at the time of death.

The patient or family and the clinical care team should discuss organ and tissue donation, if appropriate, before death or immediately after death; such discussions are ordinarily mandated by law. The attending physician should know how to arrange for organ donation and autopsy, even for patients who die at home or in a nursing home. Autopsy should be readily available regardless of where the death occurred, and decisions about autopsies can be made before death or just after death. A minority of families welcomes

an autopsy to clear up uncertainties, and clinicians should appreciate the role of autopsy in quality assessment and improvement.

Hospice Care

Hospice is a concept and a program of care that is specifically designed to minimize suffering for dying patients and their family members. In the United States, hospice is the only widely available comprehensive program to support very sick people at home. Philosophically, hospice programs forgo most diagnostic testing and life-prolonging treatments in favor of symptom relief, education of patients and family members about appropriate care, and comfort care.

Hospice is always interdisciplinary, relying on a core team of physicians, nurses, social workers, and attendants, such as home health aides. Pharmacists, nutritionists, and therapists may also be involved. Hospice program personnel care for patients at home, in nursing homes, or in other care facilities. Although hospice program personnel do not usually care for patients in hospitals and rehabilitation centers, many hospitals are establishing palliative care programs to address the same care issues.

Hospice programs differ substantially in the services they provide and in treatments and devices they use. Whether a particular patient and family should participate in a given program depends on their needs and wishes, on their financial considerations, and on the skills and capacity of the local programs.

Hospice care can provide most necessary medical treatments. Nurses ordinarily oversee and implement the general plan of care, including drug use, O₂ therapy, and IV lines or other special equipment. Nurses are usually the first ones to assess and address patient needs. They can usually adjust drug doses and help obtain any new drugs or treatments. Hospice physicians see patients when needed and share in shaping the plan of care. Social workers, chaplains, and volunteers help address interpersonal, spiritual, and financial issues. Bereavement counselors support survivors through the grieving process. Hospice plans of care help family members prepare for the challenges of facing the death of a loved one and dealing with the situation at the time of death, including their role and how to obtain needed help.

Most patients ill enough to require hospice also require some assistance with daily activities such as dressing, bathing, and preparing food; some may be completely dependent. Family members and friends often provide this care, but additional help from home health aides and volunteers may be necessary.

Medicare or insurance mostly pays a per diem rate that is intended to cover all hospice services, including a negotiated amount of help from home health aides, but only after a physician certifies that the patient has a fatal disorder with life expectancy less than 6 months.

Physicians may be reluctant to use hospice because a treatable condition could develop. However, this reluctance is not justified because many treatable conditions are within the scope of hospice care, and patients also can leave hospice at any time and re-enroll later.

Other concerns

Patient, family, and clinicians should plan for increasing disability. Obtaining payment for end-of-life care may be difficult. Emphasis should be on improving quality of end-of-life, not on hastening death.

Progressive disability often accompanies fatal illnesses. Patients may gradually become unable to tend to a house or an apartment, prepare food, handle financial matters, walk, or care for themselves. Most dying patients need help during their last weeks. Disability should be anticipated and appropriate preparations made such as choosing housing that is wheelchair-accessible and close to family caregivers. Services such as occupational or physical therapy and hospice care may help a patient remain at home, even when the disability progresses.

Financial coverage for care of dying patients is problematic. Medicare regulations restrict payment for many aspects of supportive care. Not all patients qualify for hospice care, and physicians are often reluctant to certify the 6-month prognosis required for hospice coverage. Sometimes the need for skilled nursing care can justify Medicare payment to a nursing home for short-term, complex medical and nursing needs for dying patients. One study has shown that 1/3 of families deplete most of their savings when caring for a dying relative. The clinical care team should know the financial effects of choices and discuss these issues with patients or family members. Some attorneys specialize in elder care and can help patients and their family members deal with these issues.

Legal and ethical concerns are important and health care practitioners should know local laws and institutional policy governing living wills, durable powers of attorney, and procedures for forgoing resuscitation and hospitalization. This knowledge helps them ensure that the patient's wishes guide care, even when the patient can no longer make decisions.

Many health care practitioners worry that medical treatments intended to relieve pain or other suffering can hasten death, but this is actually quite uncommon. With thoughtful and skillful medical care, accusations of assisted suicide or other wrongdoing are almost nonexistent. Even if dyspnea requires doses of opioids that may also hasten death, the resulting death is not considered wrongful.

However, actually assisting with suicide, by directly providing a dying patient with lethal drugs and instructions for using them, could be grounds for prosecution in most states but is authorized under specific conditions in Oregon. Charges of homicide are plausible if the patient's interests are not carefully advocated, if the patient lacks capacity or is severely functionally impaired when decisions are made, if decisions and their rationales are not documented, or if the prosecutor's electoral base is expected to approve of such charges. Physicians who manage symptoms vigorously and forgo life-sustaining treatment need to document decision making carefully; provide care in a reputable setting; and discuss these issues willingly, honestly, and sensitively with patients, other practitioners, and the public. A physician should not provide an intervention that is conventionally considered a means of homicide, such as lethal injection, even if the intention is to relieve suffering.

Symptom Control in the Dying

Patients need reassurance that symptoms will never be overwhelming. Physical and mental distress is common while living with fatal illness, but much distress can be prevented or relieved. Patients commonly fear protracted and unrelieved suffering. Knowing they can count on living reasonably comfortably enables patients to focus on

living as fully as possible and on confronting the issues presented by fragile health and the approach of death.

Symptom control should be based on etiology when possible. For example, vomiting due to hypercalcemia requires different treatment from that due to elevated intracranial pressure. However, diagnosing the cause of a symptom may be inappropriate if testing is burdensome or risky or if specific treatment, such as major surgery, has already been ruled out. For dying patients, comfort measures, including nonspecific treatment or a short sequential trial of empiric treatments, are often better than an exhaustive diagnostic evaluation.

Because one symptom can have many causes and may respond differently to treatment as the patient's condition deteriorates, the clinical team must monitor and reevaluate the situation frequently. Drug overdosage or underdosage is harmful, and both become more likely as worsening physiology causes changes in drug disposition.

When survival is likely to be brief, symptom severity frequently dictates initial treatment.

Sometimes the fear that a symptom will worsen can be more crippling than the symptom itself, and reassurance that effective treatment is available may be all a patient needs.

When a symptom is quite severe or the diagnostic alternatives do not affect treatment, the physician should quickly relieve suffering by treating the symptom.

Pain

About half of patients dying of cancer have severe pain. Yet, only half of these patients receive reliable pain relief. Many patients dying of organ system failure and dementia also have severe pain. Sometimes pain can be controlled but persists because patients, family members, and physicians have misconceptions about pain and the drugs, especially opioids that can control it, resulting in significant underdosing.

Patients perceive pain differently, partly depending on whether other factors such as fatigue, insomnia, anxiety, depression, nausea are present. Analgesic choice depends largely on pain intensity and cause, which can be determined only by talking with and observing patients. Patients and physicians must recognize that all pain can be relieved by an appropriately potent drug at sufficient dosage, although aggressive treatment may also cause sedation or confusion. Commonly used drugs are aspirin, acetaminophen, or NSAIDs for mild pain; oxycodone for moderate pain; and hydromorphone, morphine, or fentanyl for severe pain.

In dying patients, oral opioid therapy is most convenient and cost effective. Rectal opioid therapy provides more uneven absorption. Morphine suppositories or pills may be given rectally at the same dosage used for oral forms and then titrated as needed. IV or subQ opioid therapy is better than IM injections, which are painful and result in variable absorption. Long-acting opioids are best for long-lasting pain. When giving opioids, the physician should prescribe them in adequate dosage and on a continuous basis to prevent pain. Unreasonable concerns by the public and by health care practitioners about addiction often tragically limit appropriate use of opioids. Pharmacologic dependence may result from regular use but causes no problems in dying patients except the need to avoid inadvertent withdrawal. Addictive behaviors are rare and usually easy to control. Adverse effects of opioids include nausea, sedation, confusion, constipation, and respiratory depression. Constipation should be treated prophylactically. Patients usually develop substantial tolerance to the respiratory depressant and sedative effects of

morphine but have much less tolerance for the analgesic and constipating effects. Opioids may also cause myoclonus (involuntary twitches or jerks), agitated delirium, hyperalgesia, and seizures. These effects may result from accumulation of toxic metabolites and usually resolve when another opioid is substituted. Patients with these adverse effects and serious pain often warrant consultation with a palliative care specialist or pain specialist.

When a stable opioid dose becomes inadequate, increasing the dose by 1.5 to 2 times the previous dose is reasonable. Usually, serious respiratory depression does not occur unless the new dose is much more than twice the previously tolerated dose. Clinicians often are unfamiliar and thus uncomfortable with such large dosage increases. Increasing the dose over 1 to 2 hours with constant observation and having opioid antagonists immediately available can overcome that reluctance.

Use of adjunctive drugs for pain control often increases comfort and reduces the opioid dosage and consequent adverse effects. Corticosteroids can reduce the pain of inflammation and swelling. Tricyclic antidepressants, such as nortriptyline or doxepin help manage neuropathic pain; doxepin can provide bedtime sedation as well. Gabapentin helps relieve neuropathic pain. Methadone is effective for refractory or neuropathic pain; however, its kinetics vary and it requires close monitoring. Benzodiazepines are useful for patients whose pain is worsened by anxiety.

For severe localized pain, regional nerve blocks given by an anesthesiologist experienced in pain management may provide relief with few adverse effects. Various nerve-blocking techniques may be used. Indwelling epidural or intrathecal catheters can provide continuous infusion of analgesics, often mixed with anesthetic drugs.

Pain-modification techniques such as guided mental imagery, hypnosis, acupuncture, relaxation, and biofeedback help some patients. Counseling for stress and anxiety may be very helpful, as may spiritual support from a chaplain.

Dyspnea

Dyspnea is one of the most feared symptoms and is extremely frightening to dying patients. Quickly reversible causes should be treated specifically. For example, placing a chest tube for tension pneumothorax or performing thoracentesis for a pleural effusion provides quick and definitive relief. However, if death is imminent or a definitive treatment for the cause of dyspnea is not available, proper symptomatic treatment assures patients they will be comfortable, regardless of the cause.

As a first intervention, O₂ helps correct hypoxemia. Even when its oxygenating benefit is no longer certain, O₂ may continue to be psychologically comforting to patients and family members. O₂ therapy is most comfortable by nasal cannula, so this route is preferred unless higher concentrations are critically important.

Morphine helps reduce breathlessness in a patient. A low dose of morphine may blunt the medullary response to CO₂ retention or O₂ decline, reducing dyspnea and decreasing anxiety without causing harmful respiratory depression. If patients are already taking opioids for pain, dosages that relieve dyspnea must often be more than double the patient's usual dosages.

Airway congestion is best managed with drugs that dry secretions. Nebulized saline may help patients with viscous secretions. Bronchospasm and bronchial inflammation may abate with nebulized albuterol and oral or injectable corticosteroids.

Benzodiazepines often help relieve anxiety associated with dyspnea and with the fear of a return of dyspnea. Useful nondrug measures include providing a cool draft from an open window or fan and maintaining a calming presence.

Anorexia

Anorexia and marked weight loss are common among dying patients. For family members, accepting the patient's poor oral intake is often difficult because it means accepting that the patient is dying. Patients should be offered their favorite foods whenever possible. Conditions that may cause poor intake that can be easily treated such as gastritis, constipation, toothache, oral candidiasis, pain, and nausea, should be treated. Some patients benefit from appetite stimulants such as oral corticosteroids. However, if a patient is close to death, family members should understand that neither food nor hydration is necessary to maintain the patient's comfort.

IV fluids, TPN, and tube feedings do not prolong the life of dying patients. All of these measures seem to increase discomfort and may hasten death. Pulmonary congestion and pneumonia are more common among dying patients who are fed artificially. Artificial hydration may worsen edema and pain associated with inflammation. Conversely, dehydration and ketosis due to caloric restriction correlate with analgesic effects and absence of discomfort. The only reported discomfort due to dehydration near death is xerostomia (dry mouth due to a lack of saliva), which is easily relieved with oral swabs or ice chips.

Family members should be gently told that the patient is dying and that food does not help the patient's strength nor substantially delay death; they should be reassured that the patient does not suffer from having little or no intake. Having family members and friends take on specific tasks such as providing favorite foods, small portions, and foods that are easy to swallow, provides other ways to show caring and love, which can help family members.

Even debilitated and cachectic (loss of weight, muscle atrophy, fatigue, weakness and significant loss of appetite) patients may live for several weeks with no food and minimal hydration. Family members should understand that stopping fluids does not result in the patient's immediate death and ordinarily does not hasten death. Supportive care, including good oral hygiene, is imperative for patient comfort during this time.

Nausea and Vomiting

Many seriously ill patients experience nausea, frequently without vomiting. Nausea may arise with GI problems, such as constipation or gastritis, metabolic abnormalities, such as hypercalcemia or uremia, drug adverse effects, increased intracranial pressure secondary to cerebral cancer, and psychosocial stress. When possible, treatment should match the likely cause; may need to stop NSAIDs and treat gastritis with H₂ blockers, and try corticosteroids for patients with known or suspected brain metastases. If nausea is due to gastric distention and reflux, metoclopramide is useful because it increases gastric tone and contractions while relaxing the pyloric sphincter.

Patients with no specific cause of nausea may benefit from treatment with a phenothiazine. Anticholinergic drugs such as scopolamine and the antihistamines meclizine and diphenhydramine prevent recurrent nausea in many patients. Combining lower doses of drugs often improves efficacy. Second-line drugs for intractable nausea

often dramatically relieve chemotherapy-induced nausea. Cost often makes these antagonists 2nd-line drugs for more complex causes of nausea in dying patients. Nausea and pain due to intestinal obstruction are common among patients with widespread abdominal cancer. Generally, IV fluids and nasogastric suction are more burdensome than useful. Symptoms of nausea, pain, and intestinal spasm respond to hyoscyamine, scopolamine, morphine, or any of the other antiemetics. Octreotide inhibits GI secretions and dramatically reduces nausea and painful distention. Given with antiemetics, octreotide usually eliminates the need for nasogastric suctioning. Corticosteroids may decrease obstructive inflammation at the tumor site and temporarily relieve the obstruction. IV fluids may exacerbate obstructive edema.

Constipation

Constipation is common among dying patients because of inactivity, use of opioids and drugs with anticholinergic effects, and decreased intake of fluids and dietary fiber. Regular bowel movements are essential to the comfort of dying patients, at least until the last day or two of life. Laxatives help prevent fecal impaction, especially in patients receiving opioids. Monitoring bowel function regularly is essential. Most patients do well on a twice/day regimen of stool softener plus a mild stimulant laxative. If stimulant laxatives cause cramping discomfort, patients may respond to increased doses of docusate alone or an osmotic laxative.

Pressure Ulcers

Many dying patients are immobile, poorly nourished, incontinent, and cachectic and thus are at risk of pressure ulcers. Prevention requires relieving pressure by rotating the patient or shifting the patient's weight every 2 hours; a specialized mattress or continuously inflated air-suspension bed may also help. Incontinent patients should be kept as dry as possible. Generally, use of an indwelling catheter, with its inconvenience and risk of infection, is justified only when bedding changes cause pain or when patients or family members strongly prefer it.

Confusion

Mental changes that can accompany the terminal stage of a disorder may distress patients and family members; however, patients are often unaware of them. Confusion (delirium) is common; causes include drugs, hypoxia, metabolic disturbances, and intrinsic CNS disorders. If the cause can be determined, simple treatment may enable patients to communicate more meaningfully with family members and friends. Patients who are comfortable and less aware of their surroundings may do better with no treatment. When possible, the physician should ascertain the preferences of patients and family members and use them to guide treatment.

Simple causes of confusion and agitation should be sought. Agitation and restlessness often result from urinary retention, which resolves promptly with urinary catheterization. Confusion in debilitated patients is worsened by sleep deprivation. Agitated patients may benefit from benzodiazepines; however, benzodiazepines may also cause confusion. Poorly controlled pain may cause insomnia or agitation. If pain has been appropriately controlled, a nighttime sedative may help.

Family members and visitors may help lessen confusion by frequently holding the patient's hand and repeating where the patient is and what is happening. Patients with

severe terminal agitation resistant to other measures may respond best to barbiturates; family members should be made aware that, when near death, patients do not usually wake up much after starting these drugs. Pentobarbital, a rapid-onset, short-acting barbiturate, may be given.

Depression

Most dying patients experience some depressive symptoms. Providing psychological support and allowing patients to express concerns and feelings are usually the best approach. A skilled social worker, physician, nurse, or chaplain can help with these concerns.

A trial of antidepressants is often appropriate for patients who have persistent, clinically significant depression. Depressed patients with anxiety and insomnia may benefit from a sedating tricyclic antidepressant given at bedtime. For patients who are withdrawn or who have vegetative signs, methylphenidate may be started and can provide a few days or weeks of increased energy for patients who are fatigued or somnolent because of analgesics. Methylphenidate has a rapid effect but may precipitate agitation. Although its duration of action is short, adverse effects are also short-lived.

Stress

A few people approach death peacefully, but more patients and family members experience stressful periods. Death is particularly stressful when interpersonal conflicts keep patients and family members from sharing their last moments together in peace. Such conflicts can lead to excessive guilt or inability to grieve in survivors and can cause anguish in patients. A family member who is caring for a dying relative at home may experience physical and emotional stress. Usually, stress in patients and family members responds to compassion, information, counseling, and sometimes brief psychotherapy. Community services may be available to help relieve caregiver burden. Sedatives should be used sparingly and briefly.

When a partner dies, the survivor may be overwhelmed by having to make decisions about legal or financial matters or household management. For an elderly couple, the death of one may reveal the survivor's cognitive impairment, for which the deceased partner had compensated. The clinical team should identify such high-risk situations so that they can mobilize the resources needed to prevent undue suffering and dysfunction.

Grief

Grieving is a normal process that usually begins before an anticipated death. For patients, grief often starts with denial caused by fears about loss of control, separation, suffering, an uncertain future, and loss of self. Traditionally, the stages after grief were thought to occur in the following order: denial, anger, bargaining, depression, and acceptance. However, the stages that patients go through and their order of occurrence vary. Members of the clinical team can help patients accept their prognosis by listening to their concerns, helping them understand that they can control important elements of their life, explaining how the disorder will worsen and how death will come, and assuring them that their physical symptoms will be controlled. If grief is very severe, causes psychosis, or an idea of suicide, or if the patient has a previous severe mental disorder, then referral for professional evaluation and grief counseling may be needed.

Family members may need support in expressing grief. Any clinical team member who has come to know the patient and family members can help them through this process and direct them to professional services if needed. Physicians and other clinical team members need to develop regular procedures that ensure follow-up of grieving family members.

Do-Not-Resuscitate (DNR) Orders

The do-not-resuscitate (DNR) order placed in a patient's medical record by a physician informs the medical staff that CPR should not be done. This order has been useful in preventing unnecessary and unwanted invasive treatment at the end of life.

Physicians discuss with patients the possibility of cardiopulmonary arrest, describe CPR procedures, and ask patients about treatment preferences. If the patient is incapable of making a decision about CPR, a surrogate may make the decision based on the patient's previously expressed preferences or, if such preferences are unknown, in accordance with the patient's best interests.

Almost all states have specialized DNR protocols for patients who are living at home or in any nonhospital setting. These protocols typically require the signing of an out-of-hospital DNR order by both the physician and patient (or the patient's surrogate) and the use of a special identifier (a bracelet or brightly colored form) that is worn by or kept near the patient. If emergency medical personnel are called in case of emergency and see an intact identifier, they will provide comfort care only and not attempt resuscitation. These protocols are important to know, because, normally, emergency medical technicians are not expected to read or rely upon a living will or durable power of attorney for health care.

A DNR order does not mean "do not treat." Rather, it means only that CPR will not be done. Other treatments, such as antibiotic therapy, transfusions, dialysis, or use of a ventilator that may prolong life can still be provided. CPR itself usually does not result in long-term, neurologically intact survival, but other treatments, including aggressive or critical care that prevents cardiac arrest, can. Thus, whether to pursue other treatments is a more important decision than whether to resuscitate. A person with a DNR order can still be treated aggressively in an intensive care unit if their condition warrants.

Advance Directives

Living will expresses preferences for end-of-life care. Durable power of attorney for health care designates a surrogate decision maker.

Patients' wishes as to what health care should be provided when their capacity to make decisions is lost should be respected. Advance directives are legal documents that extend personal control over these decisions. They are called advance directives because they direct preferences for medical care in advance of incapacitation. Advance directives are recognized in every state of the U.S. There are two primary types, a living will and a durable power of attorney for health care. All states have recognized and defined these documents by statute with the goal of providing a simple legal tool by which people can express their wishes and have them honored. However, they are not the exclusive means available to express wishes. Any authentic expression of a patient's wishes should be respected.

An advance directive cannot be completed after a patient becomes mentally incapacitated and, in most states, it does not become effective until after incapacity has been

determined. If no advance directive has been prepared, an authorized surrogate must be identified or appointed to make medical care decisions.

A living will expresses a patient's preferences for end-of-life medical care. It is called a "living" will because it is in effect while the person is still alive. In some states, the document is called a directive to doctors or a declaration. State laws vary greatly regarding scope and applicability of living wills.

A living will allows people to express preferences for the amount and nature of their medical care, from no interventions to maximum care. Detailed treatment preferences are desirable because they provide more specific guidance to practitioners. A living will cannot compel health care practitioners to provide medical care that is medically or ethically unwarranted.

To be valid, a living will must comply with state law. Some states require that living wills be written in a fairly standardized way. Others are more flexible, permitting any language as long as the document is appropriately signed and witnessed. In most states, a health care practitioner involved in the patient's care cannot be a witness. A document that does not comply with state law requirements for statutory living wills may still serve as a valid communication of a patient's wishes as long as it is an authentic expression of the patient's wishes.

Living wills go into effect upon the loss of ability to make health care decisions or the existence of a medical condition specified in the directive, typically a terminal condition, permanent vegetative state, or the end-stage of a chronic condition. Often, state law provides a process for confirming and documenting the loss of decisional capacity and the medical condition.

Durable power of attorney for health care is a document in which one person (the principal) names another person (the agent, proxy, or the attorney-in-fact) to make decisions about health care and only health care. In most states, these documents become legally effective when the principal loses clinical capacity to make health care decisions. Some states recognize immediately effective durable powers of attorney for health care, but as a practical matter, the principal retains decision-making authority until incapacity regardless, so there is little practical difference. Like the living will, the durable power of attorney for health care may be referred to by different terms in different states.

While a living will states a person's specific preferences regarding medical treatment, a durable power of attorney for health care designates an agent to make health care decisions. People who have both a living will and a durable power of attorney for health care should stipulate which should be followed if the documents seem to conflict.

Because predicting future circumstances in all of their complexity is virtually impossible and because the durable power of attorney for health care designates a decision maker who can respond to here-and-now circumstances, a durable power of attorney is far more practical and flexible than a living will. The agent is granted the power to discuss medical alternatives with the physicians and make decisions if an accident or illness incapacitates the person. In most states, a health care practitioner involved in the care of the patient cannot serve as agent for health care matters, unless the practitioner is a close relative. The durable power of attorney for health care can include a living will provision or any other specific instructions but, preferably, should do so only as guidance for the agent, rather than as a binding instruction.

The durable power of attorney for health care should name an alternate or successor in case the first-named person is unable or unwilling to serve as agent. Two or more people may be named to serve together (jointly) or alone (severally), although reliance on multiple concurrent agents can be problematic. A jointly held power requires that all agents agree and act together. In this arrangement, all named agents must be contacted and must agree on every decision. However, this arrangement can be unwieldy because agreement may be difficult to achieve and because one of the agents may be unreachable when a critical decision must be made. A severally held power may be more functional, because it allows any named agent to act alone. However, this arrangement can also lead to disagreement, and the courts may eventually have to become involved. For example, if two or more people serve jointly in severally held power and they absolutely cannot agree, then the parties will likely end up in court.

The use of the durable power of attorney for health care is valuable for adults of all ages. It is especially critical for unmarried couples, same-sex partners, friends, or other individuals considered legally unrelated who wish to grant each other the legal authority to make health care decisions and to ensure rights of visitation and access to medical information.

Ideally, physicians should obtain a copy of a patient's living will and durable power of attorney for health care, review the contents with the patient while the patient is still capable, and make it part of the medical record. A copy of the durable power of attorney for health care should also be given to the patient's appointed agent and another copy placed with important papers. The patient's attorney should hold a copy of all documents. An increasing number of states offer optional electronic registries for recording advance directives.

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Content last modified November 2007

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