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Providing compassionate end-of-life care

Facing the end of life is hard for everyone involved, but you can help by providing pain management and psychological support. Learn what you can do to ease the way for terminally ill patients and their families.

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The author has disclosed that she has no significant relationships with or financial interest in any commercial companies that pertain to this educational activity.

ALTHOUGH LIFE EXPECTANCY has increased dramatically in the past 100 years, we all must face the certainty of death. End-of-life care is a general term that refers to the comprehensive care given in the advanced or terminal stages of illness; in other words, helping your patient to die on her own terms to the best of your ability.

According to the Institute of Medicine, a "good" death is:

- free from avoidable distress and suffering for the patient, her family, and caregivers
- in accordance with the wishes of the patient and her family
- consistent with clinical, cultural, and ethical standards.

In this article, I'll help you gain a better understanding of how to give your adult patients the best possible quality of life at the end of their life.

What's a good death?

To explore the concept of a good death, many researchers have investigated how people want to be cared for at the end of their lives. Chronically ill patients frequently identify these five goals for quality end-of-life care:

- avoid prolonged dying
- strengthen relationships with loved ones
- relieve the burden on their loved ones
- receive adequate pain and symptom management
- achieve a sense of control.

One way to give your patient control over how she dies is to encourage her to write advance directives, such as a living will and durable power of attorney for healthcare, before she becomes disabled (see *Methods of stating end-of-life preferences*). Advance directives can be amended or canceled at any time, for any reason, such as a change in the patient's condition or if she changes her mind. Make sure you know your state's guidelines and your facility's policies regarding how advance directives are to be communicated and honored. If your patient has a living will or durable power of attorney for healthcare, ensure that a copy is placed in the medical record.

Methods of stating end-of-life preferences

Advance directives are written documents that allow the individual of sound mind to document preferences regarding end-of-life care that should be followed when the signer is terminally ill and unable to verbally communicate her wishes. The documents are generally completed in advance of serious illness, but may be completed after a diagnosis of serious illness if the signer is still of sound mind. The most common types are the durable power of attorney for healthcare and the living will:

- *Durable power of attorney for healthcare*—a legal document through which the signer appoints and authorizes another individual to make medical decisions on her behalf when she's no longer able to speak for herself; also known as a healthcare power of attorney or a proxy directive.
- *Living will*—a type of advance directive in which the signer documents treatment preferences, providing instructions for care in the event that she's terminally ill and not able to communicate her wishes directly (often accompanied by a durable power of attorney for healthcare); also known as a medical directive or treatment directive.

Criteria for hospice care

The following are eligibility criteria for hospice care.

General

- Serious, progressive illness
- Limited life expectancy
- Informed choice of palliative care over cure-focused treatment

Hospice-specific

- Presence of a family member or other caregiver continuously in the home when the patient is no longer able to safely care for herself; some hospices have created special services within their programs for patients who live alone, but this varies widely

Medicare and Medicaid hospice benefits

- Medicare Part A; medical assistance eligibility
- Waiver of traditional Medicare/Medicaid benefits for the terminal illness
- Life expectancy of 6 months or less
- Physician certification of terminal illness
- Care must be provided by a Medicare-certified hospice program

When the end is near

Consider the following scenario as I walk you through suggestions about how to care for a patient at the end of her life.

It's the beginning of your shift at the long-term-care facility where you work and the offgoing nurse tells you that Mrs. Dodd, a 76-year-old patient with end-stage renal disease, has had a fairly rough night. In accordance with her wishes as outlined in her advance directives, Mrs. Dodd was recently placed on comfort measures only after it was deemed that continuation of dialysis was futile. The access port located in her left chest wall was maintained to administer medication by I.V. push as needed.

When you assess Mrs. Dodd, you note that she's restless and frequently pulls at her clothing (caused in part by changes in metabolism). She has become nonverbal and incontinent and is exhibiting signs and symptoms of increased pain. Her pain medication has been increased to morphine, 30 mg every 4 hours via I.V. push, with a breakthrough dose of 5 mg every 2 hours as needed. To combat her increasing agitation, lorazepam, 1 mg every 4 hours via I.V. push, is ordered, with a breakthrough dose of 0.5 mg every 2 hours as needed.

During your assessment, you note bilateral rhonchi with generalized wheezing. She has audible congestion and is using auxiliary muscles to breathe. To help decrease secretions, two to four drops of atropine given buccally every 3 to 4 hours is ordered. You place the head of the bed at 30 degrees to prevent aspiration. Mrs. Dodd is experiencing sporadic periods of dyspnea, with an oxygen saturation level between 83% and 86%. Oxygen at 4 L/minute via

Signs of approaching death

- *The patient will show less interest in eating and drinking*. For many patients, refusal of food is an indication that they're ready to die. Fluid intake may be limited to that which will keep their mouths from feeling too dry. Offer, but don't force, fluids and medication. Pain or other symptoms that have required medication in the past may no longer be present. For most patients, pain medications will still be needed and can be provided by concentrated oral solutions placed under the tongue or by rectal suppository.
- *Urinary output may decrease in amount and frequency.* No response is needed unless the patient expresses a desire to urinate and can't.
- *As the body weakens, the patient will sleep more and begin to detach from the environment*. She may refuse your attempts to provide comfort. Allow her to sleep. Her family may wish to sit with her, play soft music, or hold hands. Assure the family that their loved one's withdrawal is normal and not a rejection of their love.
- *Mental confusion may become apparent, as less oxygen is available to supply the brain.* The patient may report strange dreams or visions. As she awakens from sleep, remind her of the day and time, where she is, and who's present. This is best done in a casual, conversational way.
- *Vision and hearing may become somewhat impaired, and speech may be difficult to understand.* Speak clearly but no more loudly than necessary. Keep the room as light as the patient wishes, even at night. Carry on all conversations as if they can be heard because hearing may be the last of the senses to cease functioning. Many patients are able to talk until minutes before death and are reassured by the exchange of a few words with a loved one.
- *Secretions may collect in the back of the throat and rattle or gurgle as the patient breathes through the mouth.* She may try to cough, and her mouth may become dry and encrusted with secretions. Secretions may drain from the mouth if you place the patient on her side and provide support with pillows. Cleansing the mouth with moistened mouth swabs will help to relieve the dryness that occurs with mouth breathing. Offer water in small amounts to keep the mouth moist. A straw with one finger placed over the end can be used to transfer sips of water to the patient's mouth.
- *Breathing may become irregular with periods of no breathing (apnea).* The patient may be working very hard to breathe and may make a moaning sound with each breath. As the time of death nears, her breathing will remain irregular and may become more shallow and mechanical. Raising the head of the bed may help her breathe more easily. The moaning sound doesn't mean that she's in pain or other distress; it's the sound of air passing over very relaxed vocal cords.
- *As the oxygen supply to the brain decreases, the patient may become restless.* It's not unusual for the patient to pull at the bed linens, have visual hallucinations, or even try to get out of bed at this point. Reassure her in a calm voice that you're there. Prevent her from falling when trying to get out of bed. Soft music or a back rub may be soothing.
- *The patient may feel hot one moment and cold the next as the body loses its ability to control the temperature.* As circulation slows, the arms and legs may become cool and bluish. The underside of the body may darken. It may be difficult to feel a pulse at the wrist. Provide and remove blankets as needed. Avoid using electric blankets, which may cause burns because the patient can't tell you if she's too warm. Sponge her head with a cool cloth if this provides comfort.
- *Loss of bladder and bowel control may occur around the time of death.* Protect the mattress with waterproof padding and change the padding as needed to keep the patient comfortable.
- *As people approach death, many times they report seeing gardens, libraries, or family or friends who've died.* The patient may ask you to pack her bags and find tickets or a passport. She may become insistent and attempt to do these chores herself. She may try getting out of bed (even if she's been confined to bed for a long time) so that she can "leave." Reassure her that it's alright; she can "go" without getting out of bed. The family may want to stay close, share stories, and be present.

nasal cannula is ordered. After 30 minutes of receiving oxygen, her oxygen saturation level is between 90% and 95% and she's breathing easier.

Mrs. Dodd has a rectal temperature of 102.6° F (39.2° C). You administer acetaminophen, 650 mg rectally, in the form of a suppository. The care plan team has deemed that I.V. therapy is contraindicated due to the risk of complicating the fluid overload already present secondary to her end-stage renal disease and cessation of dialysis. Her diet, soft with pureed meats, has been downgraded to N.P.O. with just sips of liquids or ice chips. She went from consuming almost 100% of her meals to just barely 25%, and she wasn't able to consume any portion of her last two meals.

Mrs. Dodd's family has been contacted and her daughter, two sons, five teenage grandchildren, and her sister arrive to be with her. Her husband of 50 years passed away 6 years ago. Understandably, they're anxious and look to you for what they can do for their loved one.

Besides continued assessment and keeping her comfortable, what else can you do for Mrs. Dodd and her family? Pain management and psychological support are two important aspects of end-of-life care. Your patient may also be eligible for hospice care (see *Criteria for hospice care*).

Providing physical comfort

Comfort measures include pain medication, suctioning your patient's mouth to prevent choking, splinting fractures, and other measures designed to make her more comfortable.

As her disease becomes more advanced, pain management will be more aggressive, often necessitating higher and more frequent doses of pain medications. If she's unable to swallow, medications given via patch, lollipops, or under the tongue are options.

As the body starts the natural process of dying, the need for food and fluids decreases due to the various systems shutting down (see *Signs of approaching death*). At this point, the body doesn't need food and fluids, and dehydration associated with

Assessing end-of-life beliefs, preferences, and practices

Here are questions you can ask your patient and her family to help determine their preferences for end-of-life care.

Disclosure/truth telling

- Tell me how you or your family talk about very sensitive or serious matters. Are there any topics that you or your family are uncomfortable discussing?
- Is there one person in the family who assumes responsibility for obtaining and sharing information?
- What kind of information may be shared with children in your family, and who's responsible for communicating with the children?
- What kind of/how much information should be shared with your immediate family? Your extended family? Others in the community (for example, members of a religious community)?

Decision-making style

- How are decisions made in your family?
- Who would you like to be involved in decisions about your treatment or care?

Symptom management

- How would you like us to help you to manage the physical effects of your illness?
- What medications are acceptable to you to be used for symptom relief?
- What are your beliefs regarding expression of pain and other symptoms?
- What degree of symptom management do you desire?

Life-sustaining treatment expectations

- Have you thought about what type of medical treatment you or your loved one would want as the end of life is nearing?
- Do you have an advance directive (living will or durable power of attorney for healthcare)?
- Would you like: nutrition/hydration at the end of life, CPR, ventilation, dialysis, antibiotics, or medications to treat infection?

Desired location of dying

- Do you have a preference about being at home or in some other location when you die?
- Who do you want to be involved in caring for you at the end of life?
- Are you uncomfortable having either men or women provide your care or your loved one's personal care?

Spiritual/religious practices and rituals

- Is there anything that we should know about your spiritual or religious beliefs about death?
- Are there any practices that you would like us to observe as death is nearing?

Care of the body after death

- Is there anything that we should know about how a body/your body should be treated after death?

Expression of grief

- What types of losses have you and your family experienced?
- How do you and your family express grief?

Funeral and burial practices

- Are there any rituals or practices associated with funerals or burial that are especially important to you?

Mourning practices

- How have you and your family carried on after a loss in the past?
- Are there particular behaviors or practices that are expected or required?

the dying process actually causes analgesic effects. Family members tend to want their loved one to eat and drink; however, I.V. fluids and enteral feedings don't prolong the life of dying patients. In fact, they may increase discomfort and hasten death. I.V. fluids can cause edema, increased pain from inflammation, and fluid overload, and enteral feedings can cause pulmonary congestion and pneumonia.

Help your patient's family understand that their loved one not only doesn't have the urge to eat or drink, but that she also most likely doesn't have the ability to do so; forcing eating and drinking may harm instead of help her.

To make your patient more comfortable if she's experiencing xerostomia, both premoistened oral swabs and dry swabs that can be wet with water or a mild mouthwash are available. If family members request, they can swab their loved one's mouth themselves.

Even if your patient doesn't seem to be affected by the act, it may bring some degree of peace to the family. Family members often feel helpless, and this is one way they can feel useful to their loved one.

Near the end of your patient's life, her sight may become dimmer and she may turn her head toward light sources. Keep soft, indirect lights on in the room and place pillows behind her back and under her head to help minimize discomfort. Be sure to keep her clean, dry, and turned every 2 hours and as needed, according to your facility's policy.

Turning minimizes the possibility of pressure ulcer development, which can add to your patient's discomfort. A dying patient is at greater risk for pressure ulcers due in part to her reduced nutritional intake and skin fragility as the body systems begin to shut down.

Providing psychological comfort

When a patient is told she has a terminal condition, more often than not, she'll experience some degree of denial. As the nurse, you play a major role in helping your patient and her family accept the diagnosis and become involved in care planning (see *Assessing end-of-life beliefs, preferences, and practices*). Be honest with the family and keep them informed, explaining any procedures and changes in treatments or medication.

Comfort measures include pain medication, suctioning your patient's mouth to prevent choking, and splinting fractures.

Remember that your patient still has psychological needs that need to be met. Encourage her to continue relationships with family and friends, such as visits, phone calls, and mail, as long as she's able. If she enjoys reading, family and friends may choose to read to her from her favorite books, magazines, or newspapers. As much as space allows, the family may want to bring in photos or a favorite figurine or some other favorite item. Spiritual needs should also be included in the care plan. If your patient is religious, offer to call clergy for her and her family.

Your patient may become tired easily and sleep more. Ask family and friends to plan visits at times when she's most likely to be awake and alert and to plan shorter activities that won't overexert her. Alert family members that she may have periods of unresponsiveness or confusion and that she may be disoriented to time and place. She may have conversations with people who aren't there, and she may pull at her clothing or bed linens. If your patient becomes disoriented, speak in a calm tone, gently reorienting her to her surroundings; never shake her if she doesn't respond.

Encourage family members to always speak positively in the presence of their loved one. Even if she can't speak or seems unresponsive, she can still hear. Hearing distress or sorrow in a loved one's voice can place an undue burden on a dying patient. Some patients may seem to hang on even after there's no medical reason for them to be alive. Many professionals and family alike believe that sometimes a patient may need permission from a family member or even from her caregiver to "let go."

Helping the family grieve

From nurses who work in hospitals or long-term-care facilities to the private-duty nurse, any nurse can tell you that no matter how many deaths you witness or are involved in, each one is different because each person is unique. And every patient has the right to die a good death, remaining free from pain and discomfort as much as possible and maintaining dignity to the end. This includes the handling of your patient's body and how her loved ones are treated by the staff. Remember, just because your patient has drawn her last breath doesn't mean that your duties to her are over.

After your patient has been pronounced dead by the proper officials, allow her family time alone with her after she's been bathed and dressed if they desire. Make this time as comfortable and private as possible for the family members. Gently offer any help they may need, such as confirming funeral home choice or grief counseling services. Referral for grief counseling is recommended even if your facility doesn't have an in-house program. Most of the time, family members just need to know that someone is there for them.

Comprehensive and compassionate care

End-of-life care involves both your patient and her family and includes providing physical comfort measures and maintaining emotional, psychosocial, and spiritual needs.

And it doesn't end when your patient dies but continues by ensuring the handling of her body and the comfort of her family. After following these steps, you can feel assured that you have indeed provided quality end-of-life care for your patient and her family **LPN**

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On the Web

American Association of Colleges of Nursing End-of-Life Nursing Education Consortium: **http://www.aacn.nche.edu/elnec**

AARP: End of life: **http://www.aarp.org/endoflife**

American Psychological Association: End-of-life issues and care: **http://www.apa.org/pi/eol/homepage.html**

End of Life/Palliative Education Resource Center: **http://www.eperc.mcw.edu**

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