October 2011 Vol. 9, No. 10

End-of-life care

Residents in the final stages of life will experience a variety of feelings, and their wishes need to be respected by those who provide care, especially CNAs, who interact with these individuals on a daily basis.

As a result, it is important for CNAs to understand the process a resident goes through as he or she is dying. When all treatment has stopped working, the resident and his or her family must accept the inevitable. This is not easy, however, and is often accompanied by **denial, anger,** and **depression.** At this stage, a CNA can shift the focus from curing the resident to comforting the individual in his or her final days.

This issue will explain the **rights and goals** of a dying resident, the use and discontinuation of **life-sustaining treatments,** the importance of **advance directives,** and the **CNA's role** in caring for a resident who is nearing death.

Have a good day of training, and stay tuned for next month's issue of **CNA Training Advisor,** which will cover strokes and seizures.

PROGRAM PREP

Program time

Approximately 30 minutes

Learning objectives

Participants in this activity will learn how to:

- Accommodate the rights of a dying resident
- Provide optimal end-of-life care through the relief of suffering and the acceptance of resident decisions
- Assist residents and their families during the grieving process

Preparation

- Review the material on pp. 2–4
- Duplicate the **CNA Professor** insert for participants
- Gather equipment for participants (e.g., an attendance sheet, pencils, etc.)

Method

1. Place a copy of **CNA Professor** and a pencil at each participant's seat
2. Conduct the questionnaire as a pretest or, if participants' reading skills are limited, as an oral posttest
3. Present the program material
4. Review the questionnaire
5. Discuss the answers

What is DNR?

A DNR (do not resuscitate) order means the resident does not want cardiopulmonary resuscitation performed if the resident's heart stops and if he or she stops breathing. This order does not affect anything else about the resident's care. An individual with a DNR order may still want every other kind of life-sustaining treatment.

QIS prep made simple

Unannounced Quality Indicator Surveys (QIS) can surprise any nursing home staff and management, threatening even the most prepared facilities with Stage II investigations of their protocols. *QIS in Action: Establish a Culture of Continuous Readiness* is a 30-minute DVD that guides nursing home staff on what to expect during every step of a survey team's visit. Presented by Diane Brown, this video will help you reduce stress on staff with insight into a surveyor's approach during the QIS.

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END-OF-LIFE CARE

According to the medical model of dying, there comes a time when all possible treatments have been tried and there is nothing left that will prevent the death of the resident. When doctors, nurses, and CNAs reach this point, they might stop giving good care to a dying person because they feel there is nothing more that can be done. They may feel they have lost control because they can't fix the problem, and may feel helpless and guilty. These feelings can lead them to avoid the dying person. Residents at the end of life can sense these feelings in their CNAs, and they may fear being abandoned. This fear increases their loneliness and discomfort.

The caring model of dying says the end of life is an important period for an individual. During this final phase, curing the problem is no longer possible, and the focus shifts to caring for the person. When CNAs think this way, they concentrate on the many things they can do to make a dying person more comfortable, to improve the quality of the dying person's life, and to provide opportunities for the person to meet his or her final life goals. When CNAs focus on caring, they shift their energies from whether the person will die to how he or she will die. Helping to relieve pain and other symptoms, giving emotional and spiritual support, and providing family time are all things that CNAs can do to care for a dying person. In addition, dying residents possess certain rights, including:

1. An individual has the right to decide how to spend the final phase of his or her life
2. A dying person has the right to refuse treatment, including food and water, and to decide how much treatment to receive
3. A dying person has the right to as much relief from pain and suffering as is medically and legally possible

Each individual should also decide what his or her goals are for the final phase of life. CNAs can help people identify and achieve these goals, which may include things such as the following:

1. Choices about living, continued personal growth, and things the individual wants to accomplish
2. Relief from pain and other uncomfortable symptoms
3. Relief from emotional and spiritual distress
4. Enrichment of personal and family relationships
5. Transitioning the individual/family toward accepting death

Sometimes, residents with terminal illnesses have to make decisions about how much treatment they want to receive and how long they want to prolong their life. Family members may have to make these decisions when the resident is too ill to decide. Staff must respect and support these decisions even if they do not agree with them.

Life-sustaining treatment

A life-sustaining treatment is anything used to maintain one or more physical functions in a terminally ill person. This includes:

- Machines such as respirators or ventilators that help the resident breathe
- Feeding a resident by artificial means, such as through the veins or through a tube into the stomach

These treatments keep a resident alive when he or she can no longer eat, drink, or breathe without assistance.

Sometimes, a terminally ill resident or the resident's family may decide to start a treatment that will keep the resident alive. However, after some time, it might become obvious that the treatment is not meeting the goals of care or is doing more harm than good. For example, feeding someone through the veins or through a stomach tube can cause swelling, choking, difficulty breathing, discomfort, restlessness, nausea, constipation, and increased pain. If the life-sustaining treatment is causing discomfort for a terminally ill person, the person and/or family may decide to stop the therapy and let the illness take its natural course toward death.

Stopping life-sustaining treatment is legally and ethically acceptable. It is also acceptable not to start the treatment at all, if the terminally ill resident and/or family decide that the treatment is not in the resident's best interests. The benefits and the burdens of treatment should be compared when making these decisions.

Advance directives

Advance directives are any oral or written instructions that a resident has given about future medical care. These instructions are to be used if the resident becomes unable to speak for him- or herself. There are two kinds of advance directives: a living will and a medical power of attorney. A living will states the resident's medical treatment wishes in

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CNA Training Advisor (ISSN: 1545-7028 [print]; 1937-7487 [online]) is published monthly by HCPro, Inc., 75 Sylvan St., Suite A-101, Danvers, MA 01923. Subscription rate: $149/year; back issues are available at $15 each. • Copyright © 2011 HCPro, Inc. All rights reserved. Printed in the USA. Except where specifically encouraged, no part of this publication may be reproduced, in any form or by any means, without prior written consent of HCPro, Inc., or the Copyright Clearance Center at 978/750-8400. Please notify us immediately if you have received an unauthorized copy. • For editorial comments or questions, call 781/639-1872 or fax 781/639-7857. For renewal or subscription information, call customer service at 800/650-6787, fax 800/639-8511, or e-mail: *customerservice@hcpro.com.* • Visit our website at *www.hcpro.com.* • Occasionally, we make our subscriber list available to selected companies/vendors. If you do not wish to be included on this mailing list, please write to the marketing department at the address above. • Opinions expressed are not necessarily those of **CTA.** Mention of products and services does not constitute endorsement. Advice given is general, and readers should consult professional counsel for specific legal, ethical, or clinical questions.

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writing. A medical power of attorney appoints someone to make decisions about medical care when the resident cannot make them.

If there is no living will or medical power of attorney, typically the resident's spouse or a child will make medical decisions when the resident cannot make them. This person is called a surrogate. The surrogate is supposed to make any healthcare decision that the terminally ill person would have made if possible, and to act in the person's best interest.

Every state has different rules about advance directives. Federal law requires healthcare facilities and agencies that receive Medicaid or Medicare funds to inform residents of their right to issue advance directives.

The CNA's role in caring for a resident nearing death

CNAs should remember two important concepts when caring for a resident who is terminally ill: acceptance of the resident's decisions and relief of suffering through effective care.

When caring for someone who is at the end of life, CNAs must accept the person and the choices he or she makes about how to live and how to die. This includes the resident's religious beliefs, cultural values and ethnic background, and his or her wishes about things to do and people to see.

A CNA must accept the person without judging his or her decisions. A CNA's job is to listen and to encourage and support the decisions the individual makes. If a CNA finds that he or she cannot support a dying resident because the CNA feels strongly that the resident's decisions or beliefs are wrong, then the CNA must tell his or her supervisor about it. Sometimes it is necessary for the supervisor to transfer the CNA's responsibilities for the dying resident to another CNA. A terminally ill resident will probably know when a CNA disagrees with his or her choices, and this can cause the resident to feel afraid, abandoned, or defensive. In this case, it is best for someone else to care for the resident if possible.

Good care can relieve much of the pain and discomfort that a person may experience during a terminal illness. A CNA should always check to see whether the resident is uncomfortable and find ways to improve the comfort level. Some of the things CNAs can do include the following:

- Position pillows comfortably
- Position the resident's body comfortably
- Moisten the lips and mouth
- Provide good oral care
- Rub lotions on the skin
- Watch for skin breakdown
- Notify their supervisor about any pain the resident is experiencing

Pain is not the only symptom that should be relieved. CNAs should report nausea, constipation, anxiety, depression, difficulty breathing, and other symptoms to their supervisor so the supervisor can suggest medications or other means to treat the ailments.

When a resident is dying, the need and desire for food and water decrease. A CNA should not force food or water on a resident who doesn't want it. Remember that a competent resident has the right to refuse any treatment, including food and water. Often a terminally ill resident will have a craving for a particular food, but when it is provided, he or she may only take one or two bites and be finished.

The best thing to do is get the resident the food he or she wants if at all possible, but do not force the resident to eat it—remember, one bite may satisfy the craving. A dying person may not want to drink anything, but his or her lips, mouth, and throat might get dry. You can relieve this discomfort by providing small sips of liquid, ice chips, hard candy, and oral hygiene. A CNA should not force a resident to drink more than he or she wants.

Don't be worried about "starving" someone to death if he or she has a terminal illness. The illness is causing death; death is not caused by the decrease in food and water. If the person is allowing the natural processes of death to occur, he or she will only want enough food and water to be comfortable.

Providing food and water only when necessary can allow chemical processes to occur in the body that actually decrease pain and discomfort. Forcing food and water on a dying person can greatly increase pain and suffering.

The grieving process

During the grieving process, the resident and his or her family go through many emotions. It's during this time that CNAs can further help the resident deal with his or her impending death.

At first, many dying residents are in denial about their fate and may do the following:

- Exhibit false hope, tell untrue stories, refuse care, and refuse to follow directions.
- Deny that a problem exists. They may make statements like, "I know the doctor is wrong."
- Deny or ignore the loss, hoping it will go away. Residents may use magical thinking, fantasy, or regression. Denial and disbelief will diminish as a resident acknowledges the impact of the impending loss and the accompanying feelings.

CNAs can help residents in denial by doing the following:

- Understand that denial helps protect and insulate the resident from the intensity of the loss.
- Paraphrase what the resident says. Avoid confirming or denying the fact that the resident is dying.
- Listen. Sometimes just being present is the greatest gift you can give to a grieving person.

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- Hold the resident's hand, offer a hug, or just acknowledge what he or she is going through by saying, "This must be so hard for you," and providing support.

Dying residents may feel anger toward staff, themselves, family members, and the doctor, and act out by doing the following:

- Become outraged at the steps they must take because of the loss
- Select scapegoats on which to vent their anger

CNAs can help residents with feelings of anger by doing the following:

- Listen and provide support. Allow the resident to express the anger rather than holding it in.
- Try to identify the reasons for the resident's anger.
- Comply with reasonable requests quickly.
- Explain that the anger is part of the grieving process.
- Let the resident know that he or she has a right to have and express these feelings.

At times, residents may try to bargain to live longer by doing the following:

- Requesting favors from a higher power.
- Asking for healing or more time in exchange for something.
- Wishing to live to see a family event, such as the birth of a grandchild, wedding, or graduation.
- Promising to do anything if the loss will go away. He or she may take extreme measures to eliminate the impending loss, including shopping around or looking for miracle cures. The resident also may take physical, emotional, or financial risks in an attempt to eliminate the inevitability of death.

CNAs can help residents by doing the following:

- Comply with requests, if possible
- Listen to the resident's concerns and provide support, but avoid giving the resident false hope

Residents who are suffering from depression may experience the following:

- Decreased concentration, insomnia, fatigue, crying, poor appetite, and lack of interest in people and the environment.
- Regrets about things they have said or done throughout life. During this stage, residents may be overwhelmed by the anguish, pain, and hurt of the impending loss.
- Uncontrollable spells of weeping, sobbing, and crying.
- Periods in which they are silent, melancholy, or morose.

CNAs can help depressed residents by doing the following:

- Avoid dismissing the resident's pain and fears.
- Avoid trying to cheer up the resident.
- Avoid telling the resident that things could be worse.
- Listen, provide support, and show that you care. The resident needs the support to regroup and reframe his or her life.

Residents who accept their fate may experience the following:

- Feelings of peacefulness.
- A decline in emotional pain.
- The ability to discuss the loss rationally and view the risks, limitations, terms, and conditions of treatment objectively. However, despite a shift toward acceptance, residents may still experience periods of denial, bargaining, anger, and despair.

CNAs can help residents accept death by doing the following:

- Avoid assuming that the resident is not afraid to die
- Listen, provide support, and show that you care about the resident

If CNAs follow these tips, they can help ease the discomfort and emotional stress affecting their terminally ill residents during the dying process. ■

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Mark the correct response.

Name: Date:

1. All of the following are types of care that CNAs should provide to dying residents except _________.

a. helping to relieve pain and other symptoms

b. giving emotional and spiritual support

c. taking a chance with one last treatment

d. providing family time

2. A dying person has the right to as much relief from pain and suffering as medically and _________ possible.

a. legally

b. ethically

c. morally

d. none of the above

3. A _________ treatment is anything used to maintain one or more physical functions in a terminally ill person.

a. terminal

b. machine

c. tube

d. life-sustaining

4. There are two kinds of advance directives: a living will, which states the resident's medical treatment wishes in writing, and a(n) _________.

a. surrogate

b. medical power of attorney

c. appointed physician

d. official family representative

5. The two critical concepts that CNAs should implement when caring for a resident who is terminally ill are _________ and relief of suffering through effective care.

a. denial

b. withdrawal

c. sympathy

d. acceptance of resident's decisions

6. If a CNA finds it impossible to support a dying resident because he or she feels strongly that the resident's decisions or beliefs are wrong, a supervisor may need to transfer the CNA's responsibilities for the dying resident to another CNA.

a. True

b. False

7. All of the following are ways that a CNA can improve a dying resident's comfort level except ________.

a. repositioning pillows

b. moistening the resident's lips and mouth

c. making the resident eat or drink

d. rubbing lotions on the skin

8. Pain is the only symptom in a dying resident that a CNA needs to report to his or her supervisor.

a. True

b. False

9. At first, many dying residents are in denial about their fate and may _________.

a. exhibit false hope

b. tell untrue stories

c. refuse to follow directions

d. all of the above

10. CNAs can help residents accept death by listening and providing support.

a. True

b. False