Caring at the End of Life

Lesson Plan

To use this lesson for self-study, the learner should read the material, do the activity, and take the test. For group study, the leader may give each learner a copy of the Learner's Guide and follow this plan to conduct the lesson. You may copy certificates for everyone who completes the lesson and passes the test. ***Approximate time: One hour.***

Objectives

At the conclusion of this lesson, participants will:
1. Be able to discuss the difference between curing and caring.
2. Know the goals of end-of-life care.
3. Understand the rights, issues, and decisions of end-of-life care.
4. Know the meaning and purpose of advance directives.
5. Be able to describe his/her role in providing care for people who are dying or have terminal illnesses.

Preparation

1. Obtain poster board and markers for each participant or group.
2. Copy the Learner's Guide for each participant.

Activity

Ask participants to fill out the ***End-of-Life Issues Survey***, answering the questions with their own personal thoughts and ideas. There are no correct or incorrect answers to this quiz. Ask if anyone is willing to explain some of his or her answers to the group. Discuss the questions.

Lesson

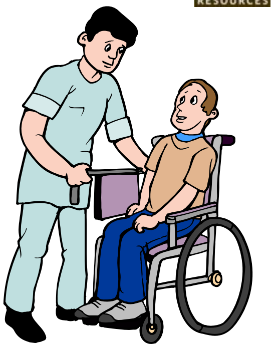
1. Remind participants that everyone's life will end someday. When we work with hospice clients, the people we care for are dying. Death is an inevitable part of life. We need to consider how we can help people through this period at the end of life.
2. Help participants go over the information on *Two Ways to View the End of Life* in the Learner's Guide.
3. Provide participants with poster board and markers and ask them to make a poster about one of the *Rights of a Dying Person*. If appropriate, post these in your training room as reminders.
4. Review the *Goals of End-of-Life Care*, and then discuss the *Important Issues and Decisions*.
5. Emphasize ways caregivers can help a terminally ill person, using the concepts on the last page of the Learner's Guide. After the discussion, ask participants if any of them have changed their ideas or beliefs about the end of life.

Evaluation

Have the learners take the test, and grade the test together. Hand out certificates to those who answer at least nine (9) of the questions correctly.

Test Answers: 1. Life-sustaining; 2. Caring; 3. Pain; 4. Emotional; 5. Oral hygiene; 6. Accept; 7. Depression; 8. Instructions; 9. Decrease; 10. Food; 11. Transfer; 12. Abandoned; 13. CPR (cardiopulmonary resuscitation)

End-of-Life Issues Survey



1. Do you believe that people should be kept alive under all circumstances?

2. What do you think makes life worth living?

3. Should someone's pain or suffering be considered in deciding how far to go to keep that person alive?

4. If you attend church or practice a faith, how does the teaching of your faith influence your feelings about death?

5. What is your idea of a good death?

Caring at the End of Life

Learner's Guide

Two Ways to View the End of Life

Curing

The ***medical model*** of dying says that sometimes all possible treatments have been tried and there is nothing left to do. In this view, we must "give up" because there is no other choice.

When caregivers think this way, they might quit giving good care to a dying person because they feel there is nothing more that can be done. They 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. People can sense this in their caregivers, and they may fear being abandoned. This fear increases their loneliness and discomfort.

Caring

The ***caring model*** of dying says the end of life is an important time. During this final phase, we focus on caring for the person instead of trying to cure them. We concentrate on the many things that can help make a dying person comfortable, improve the quality of life, and provide opportunities for the person to meet his or her final life goals.

When caregivers focus on caring, they shift their energies from ***whether*** the person will die to ***how*** they will die. Helping to relieve pain and other symptoms, giving emotional and spiritual support, and providing family time are good, caring things to do for a dying person.

The Rights of a Dying Person

1. A dying person has the right to decide what to do during the final phase of life.
2. A dying person has the right to decide where to be during the final phase of life.
3. A dying person has the right to decide who to be with, or who not to be with.
4. A dying person has the right to make decisions about treatment.
5. A dying person has the right to refuse treatment.
6. A dying person has the right to as much relief from pain and suffering as possible.
7. A dying person has the right to control how his or her remaining time is spent.

The Goals of End-of-Life Care

Each individual should decide what his or her goals are for the final phase of life. Caregivers can help people identify and achieve these goals. Goals may include:

1. Personal desires, such as continued personal growth and accomplishment.
2. Relief from pain and other uncomfortable symptoms.
3. Relief from emotional and spiritual distress.
4. Enrichment of personal and family relationships.
5. Transition of individual and family toward death.

Important Issues and Decisions

Sometimes people with terminal illnesses have to make decisions about how much treatment they want to have and how long they want to prolong life. Family members may have to make these decisions when the individual is too ill to decide. We must respect and support these decisions even if we do not agree with them—adults have the right to make these decisions.

Life-Sustaining Therapies

A life-sustaining treatment is anything used to maintain one or more physical functions in a terminally ill person. This includes machines that breathe for the person, usually called respirators or ventilators. It also includes feeding someone by artificial means, such as through the veins or through a tube into the stomach. Therapies like this keep a person alive when they can no longer eat or drink or breathe without help.

Withholding and Withdrawing Treatment

Sometimes a dying person (or the family) may decide to let a doctor start a treatment that will sustain life. After a time, it might become obvious that the therapy 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 this kind of discomfort for a terminally ill person, the person and/or his family may decide that they want to stop the therapy and let the illness take its natural course toward death.

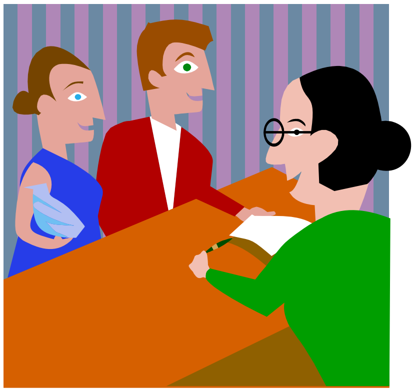
Stopping a life-sustaining therapy is legally and ethically acceptable in most cases. It is also acceptable not to start the therapy at all, if the terminally ill person and/or his family decide that the treatment is not in the person's best interests. The benefits of treatment should be compared to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

Do Not Resuscitate

An order for “Do Not Resuscitate” (DNR) means the person does not want cardiopulmonary resuscitation (CPR) performed if their heart stops and they stop breathing. It does not affect anything else about their care. An individual with a DNR order may still want every other kind of life-sustaining treatment, such as tube feeding.

Advance Directives

Advance directives are any oral or written instructions that a person has given about future medical care. These instructions are to be used if the person becomes unable to speak for himself.



There are two kinds of advance directives: a living will and a medical power of attorney. A living will states the person’s medical treatment wishes in writing. A medical power of attorney (or durable power of attorney for health care) appoints someone to make decisions about medical care when the person cannot make them. If there is no living will or medical power of attorney, the spouse, children, or parents of an individual will make medical decisions when the person cannot make them. This person is called a surrogate. The surrogate is supposed to make health care decisions that the terminally ill person would have made if possible, and to act in the person’s best interests.

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

Your Role in Caring for Someone at the End of Life

Acceptance

The first thing you must do when caring for someone who is at the end of life is to accept the person and the choices they make about how to live and how to die. You must accept their religious beliefs, values, and wishes about what they want to do and who they want to see. You must accept the person without judging his or her decisions. Your job is to listen, encourage, and support the decisions he or she makes.

If you find that it is impossible for you to support a dying person because you feel strongly that their decisions or beliefs are wrong, you must tell your supervisor about it. Sometimes it is necessary for the supervisor to transfer your responsibilities for the dying person to another caregiver. A terminally ill person often knows when a caregiver disagrees with his choices, and this can cause the person to feel afraid, abandoned, or defensive. In this case, someone else should care for the person if possible.

Relieve Suffering Through Effective Care

Good care can relieve much of the pain and discomfort that a person may experience during a terminal illness. You should always be checking to see if the person is uncomfortable, and finding ways to improve the comfort level.

Some things you can do to relieve discomfort:

- Position pillows comfortably
- Moisten lips and mouth
- Rub lotions on the skin
- Position body comfortably

- Give good oral care
- Watch for skin breakdown
- Keep the person clean
- Give good skin care

Pain must always be relieved. Other problems should also be addressed, such as:

- Nausea
- Constipation
- Anxiety
- Depression
- Difficulty breathing
- Swelling of stomach, hands, or feet
- Itching

These and other symptoms should be reported to your supervisor so they can be treated with medications and other therapies.

When a person is dying, the need and desire for food and water decrease. Do not force food or water on someone who doesn't want it. Competent adults have the right to refuse any treatment, including food and water. Often a terminally ill person will crave a certain food, but will take only one or two bites when they get it. Give them the food they want, but don't force them to eat it. One bite may satisfy them. A dying person may not want to drink, but the lips, mouth, and throat get dry. You can relieve this discomfort with small sips of liquid, ice chips, hard candy, and oral hygiene, without forcing them to drink more than they want.

Don't worry about "starving" someone to death if they are dying. The <u>illness</u> 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, they will only want enough food and water to be comfortable.

Giving food and water only when it is wanted can allow 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, creating a more difficult death.

Caring at the End of Life: Test

Name: ________________________________ Date: ___________ Score: _______
(9 correct answers required)

Directions: Fill in the blanks in the statements below.

1. A ______-______________________treatment is anything that maintains one or more bodily functions in a terminally ill person.
2. The "________________ model" of dying says that the end of life is a time when we concentrate on making a dying person comfortable, improving the quality of life, and providing opportunities for the person to meet goals.
3. A dying person has the right to relief from ________________ and suffering.
4. One of the goals of end-of-life care is relief from _____________________and spiritual distress.
5. You can relieve the discomfort of a dry mouth with small sips of liquid, ice chips, hard candy, and ___________ ___________________.
6. You must ____________ a terminally ill person without judging his or her decisions.
7. Nausea, constipation, anxiety, _____________________, difficulty breathing, and other symptoms should be reported to your supervisor so they can be addressed with medications or treatment.
8. Advance directives are any oral or written ____________________ that a person has given about future medical care.
9. Giving food and water only when it is wanted can allow chemical processes to occur in the body that actually _____________________ pain and discomfort.
10. Competent adults have the right to refuse any treatment, including _____________ and water.
11. Sometimes it is necessary for a supervisor to ______________ your responsibilities for a dying person to another caregiver if you cannot accept the person's beliefs.
12. People at the end of life may fear being ___________________ by their caregivers when cure is no longer possible. This fear increases their loneliness and discomfort.
13. An order for "Do Not Resuscitate" (DNR) means the person does not want ________________________ performed if their heart stops and they stop breathing.

Certificate of Completion

For Completing the One-Hour Course

End-of-Life Care

Awarded to:

____

(Name of Participant)

Date of Course: __________________________________

Organization: ____________________________________

Presented by: ____________________________________

(Signature of presenter, or write “self-study”)