

14

End-of-Life Care

Teaching 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 learning guide and follow this teaching plan to conduct the lesson. Certificates may be copied for everyone who completes the lesson.

Learning objectives

A participant in this lesson will be able to:

- Discuss the difference between curing and caring
- Know the goals of end-of-life care
- Understand the rights, issues, and decisions of end-of-life care
- Know the meaning and purpose of advance directives
- Be able to describe his or her role in end-of-life care

Activity

Introductory activity: Beliefs about dying

Ask your learners to fill out the end-of-life issues quiz (Figure 14.1), answering the questions with their own personal thoughts and ideas. There are no right or wrong answers to this quiz. Ask if anyone is willing to explain some of his or her answers to the group. Encourage the learners to discuss the questions.

Lesson activities

1. Remind your staff that everyone's life will end someday. When we work with people who are disabled, ill, or elderly, it is likely that from time to time someone we care for will die. Death is an inevitable part of life. We need to consider how we can help people through this period at the end of life.

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2. Help your workers go over the information on “Two Ways to View the End of Life.”
3. Provide your workers with poster board and markers and ask them to make a poster about one of the “Rights of a Dying Person.” If appropriate for your agency, 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” in the learning guide.
5. Emphasize ways caregivers can help a terminally ill person, using the concepts on the last page of the learning guide. After the discussion, ask your learners whether any of them have changed their ideas or beliefs about the end of life.

Conclusion

Have participants take the test. Review the answers together. Award certificates to those who answer at least seven (70%) of the test 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

Figure
14.1

End-of-Life Issues Quiz

1. Why is the end of life an important period of an individual's life?
2. What are some of the rights of the dying patient?
3. Should someone's pain or suffering be considered in deciding when the patient and/or family are ready for the hospice level of care?
4. How does the teaching of your faith or religion, if you have one, influence your feelings about death?
5. What are some of the comfort measures you, as home health staff, can provide—and teach a caregiver to provide—to the patient to assist with pain relief and discomfort during a terminal illness?

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Two Ways to View the End of Life

Curing

The “medical model” of dying says there comes a time when all possible treatments have been tried and there is nothing left to do that will prevent death. In this view, we must “give up” fighting against death when we have no other choice.

When doctors, nurses, and direct 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 at the end of life 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 period of an individual’s life. During this final phase, curing the problem is no longer possible, and the focus shifts to caring for the person. When caregivers think this way, they concentrate on the many things they can do to make a dying person 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 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 all things that caregivers can do to care for a dying person.

The Rights of a Dying Person

A dying person has the right to:

- Decide how to spend the final phase of his or her life
- Refuse treatment (including food and water) and to decide how much treatment to have
- Relief from pain and suffering, as much as is medically and legally possible

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. The goals may include things like:

- The individual's personal goals and desires, such as personal choices about living, continued personal growth, and things he or she wants to accomplish
- Relief from pain and other uncomfortable symptoms
- Relief from emotional and spiritual distress
- Enrichment of personal and family relationships
- 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

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stomach. Therapies like this keep a person alive when they can no longer eat or drink or breathe without this kind of assistance.

Withholding and withdrawing treatment

Sometimes a terminally ill person (or the family) may decide to let a doctor start a treatment that will keep the person alive. Then, after a time, it might become obvious that the therapy is not meeting the goals of care or is doing more harm than it is 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. 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 his or her heart stops and he or she stops 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.

Out-of-hospital DNR

There is a specific form designed for out-of-hospital DNR that is used in the patient's home setting. This form should be prominently displayed or immediately available should EMS personnel need it when they arrive at the patient's home.

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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 healthcare) 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 healthcare 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 healthcare facilities and agencies that receive Medicaid or Medicare funds to inform patients of their right to issue advance directives.

Your Role in Caring for Someone at the End of Life

You should remember two important concepts when caring for someone who is terminally ill.

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, the values of their cultural and ethnic background, and their wishes about what they want to do and whom 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 will probably know when a caregiver disagrees with his or her choices, and this can cause the person

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to feel afraid, abandoned, or defensive. In this case, it is best for someone else to care for the person if possible.

Relief of 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 determine whether the person is uncomfortable and finding ways to improve the comfort level. Some things you can do include:

- Position pillows comfortably
- Moisten lips and mouth
- Rub lotions on the skin
- Position body comfortably
- Provide good oral care
- Watch for skin breakdown; give skin care

Pain is not the only symptom that should be relieved. Nausea, constipation, anxiety, depression, difficulty breathing, 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 the desire for food and water decrease. You should not force food or water on someone who doesn't want it. Remember that competent adults have the right to refuse any treatment, including food and water. Often, a terminally ill person will have a craving for a particular food, but when it is brought to him or her, he or she will take only one or two bites and say he or she is finished. The best thing to do is get the patient the food he or she wants if at all possible, but don't force him or her to eat it. One bite may satisfy the craving.

A dying person may not want to drink anything, but the lips, mouth, and throat might get dry. You can relieve this discomfort with small sips of liquid, ice chips, hard candy, and oral hygiene. You should not force someone to drink more than they want.

Don't be worried about "starving" someone to death if they are dying from 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

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natural processes of death to occur, they will want only enough food and water to be comfortable. Giving food and water only when it is wanted 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 and cause a more difficult death.

TEST

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Name _____ Date _____ Score _____

Directions: Fill in the blanks in the statements below (seven out of 10 correct answers required).

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.