

End-of-life care

The rights of a dying person

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 have.
3. A dying person has the right to 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:

1. The individual's personal goals and desires, such as personal choices about living, continued personal growth, and things he or she 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. 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 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 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 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 residents and 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 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 see if 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 them, they will take only one or two bites and say they are finished. The best thing to do is get them the food they want if at all possible, but don't force them 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 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 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.