

End of Life Care

Introduction

End of life care is care for a person who is actively dying. They may have only days or weeks to live. The focus of care is keeping the person comfortable, both physically and emotionally.

“Active dying” is a term that is used to describe a person whose body systems are shutting down and who is expected to live only a few days. Have you ever wondered what happens to a person when they are actively dying?

- The lungs may become congested, causing a gurgling sound. Breathing varies in both rate and depth.
- Decreased circulation causes the limbs to become cool and take on a yellowish color. Bruise-like areas may appear.
- The person may yawn in an attempt to get more oxygen.
- Urine becomes concentrated.
- Fever may develop.
- Changes in metabolism can create an acetone odor.
- The person may become confused and restless. They may be agitated and cry out.

As death nears and consciousness decreases, they may experience Cheyne-Stokes respiration, which is an irregular pattern of breathing. Breathing may stop for up to 30 seconds. This is called apnea. They then start breathing again, often with a gasp.

When death occurs, breathing and circulation cease. Facial expression changes as the muscles relax. There is a sense that the person is no longer there.

Care Goals

Care goals at the end of life may change in level of priority or differ from previous ones. They are no longer focused on prevention and cure. The goals are now to provide physical, emotional, and spiritual comfort, and maintain quality of life.

The resident or the resident’s proxy (person appointed to make medical decisions) should be involved in setting goals in accordance with the resident’s wishes. Good communication is essential. It will make the family feel respected and valued.

As the resident's condition worsens, goals may need to be changed. For example, adequate intake may be a goal while the resident is capable of swallowing. Once they become unresponsive, a decision must be made regarding insertion of a feeding tube. If this is not the resident's wish, intake is no longer an issue. The care plan or service plan needs to be reviewed frequently and modified to meet the dying resident's changing needs.

Let's Review.

1. The focus of end-of-life care is to:
 - a) Keep the resident active;
 - b) Keep the resident comfortable; or
 - c) Keep the resident hydrated.

The correct answer is B, keep the resident comfortable. The focus of end-of-life care is keeping the resident comfortable, both physically and emotionally.

2. When a person is actively dying:
 - a) The amount of urine increases;
 - b) The limbs become warm to touch; or
 - c) Breathing becomes irregular.

The correct answer is C, breathing becomes irregular. The person may have periods of apnea, where breathing stops then starts again,

3. End-of-life care goals:
 - a) Remain the same during the dying process;
 - b) Focus on cure and prevention; or
 - c) Should be discussed with the resident/resident's proxy.

The correct answer is C, should be discussed with the resident/resident's proxy. End-of-life care goals should be in accordance with the resident's wishes.

Assessment and Pain Management

The resident should be assessed on an ongoing basis. As a caregiver, you know the resident well. You know how they react to pain and discomfort. You are the first to notice a change in the resident's condition. This makes you a valuable part of the assessment process.

When an actively dying resident is experiencing pain, the focus should be on relieving the pain and not on possible drug dependence. The most important thing is that the resident be as comfortable as possible.

Pain is easier to prevent than it is to relieve. Medication should be given before the pain becomes severe. Once pain becomes overwhelming, it can be difficult to control.

Residents with mild cognitive impairment can be asked to rate their pain on a scale of zero to ten, with zero being no pain and ten being the worst pain they can imagine. A pain scale that uses pictorial facial expressions (ranging from a happy face to a grimacing face), may be easier for some residents.

Residents with more advanced cognitive impairment will not understand how to use a scale. You can try saying, “Does something hurt?” Touch where it hurts. Your observations may be the only way to determine whether a resident with cognitive impairment is experiencing pain.

Look for signs of pain, including:

- Changes in behavior—increased agitation, fearfulness, resisting personal care, anger, sleep disturbance
- Changes in mental status—irritability, increased confusion, crying
- Verbal indications—calling out, moaning
- Pained facial expression—grimacing, frowning, rapidly blinking eyes
- Physical signs—rigid posture, holding or rubbing a part of the body, increased pulse, blood pressure, and respirations

Remember that as the resident’s caregiver, you may be able to detect signs of pain better than anyone else.

Shortness of Breath

Shortness of breath or dyspnea is common at the end of life. Raising the head of the bed can be helpful. The physician may prescribe supplemental oxygen.



Loss of Appetite

The dying resident may not feel like eating. Offer frequent, small servings. Provide foods the resident likes. Do not try to force them to eat. It is usually not painful to go without food or fluids.

Fatigue

At the end of life it is common to have little energy. Avoid unnecessary activity. Provide a bedside commode for mobile residents so they don't have to walk to the bathroom.

Let's Review

1. When medicating a dying resident for pain, care must be taken so that they do not become drug dependent. Do you agree or disagree?
 - a) Agree
 - b) Disagree

The correct answer is B, disagree. The focus should be on relieving the pain and not on possible drug dependence.

2. Which of the following may be an indication of pain in a person with cognitive impairment?
 - a) Slowed pulse
 - b) Decreased agitation
 - c) Increased confusion

The correct answer is C, increased confusion. Pain can cause the resident to become more confused.

3. Pain is easier to prevent than it is to relieve. Do you agree or disagree?
 - a) Agree
 - b) Disagree

The correct answer is A, agree. Medication should be given before the pain becomes severe. Once pain becomes overwhelming, it can be difficult to control.



4. Mrs. Burns has lost her appetite and is refusing to eat or drink. Her family believes that this will be painful. Do you agree or disagree?
- a) Agree
 - b) Disagree

The correct answer is B, disagree. It is usually not painful to go without food or fluids.

Psychosocial and Spiritual Needs in End of Life Care

Touching is important to most people, regardless of level of cognition. Hold the resident's hand. Give them a hug. Stroke their hair. If the resident enjoyed hymns, sing with them or play a CD. Pray with the resident if it is part of their spirituality and you are comfortable doing so. Talk with the resident about their past. If the resident is unable to respond, it is still important to talk to them. Hearing is the last sense to be lost.

Limit visitors to a few at a time. A room full of people can be overwhelming. If the resident does not have family members who visit, consider getting a volunteer to spend time with them. Remember to not talk about the resident as if they were not there.

Comfort Care

Comfort care is care given to the dying. Comfort care is focused on managing pain and other symptoms to keep the resident comfortable and providing support for the resident and their family. Provide a calm environment with minimum noise and soft lighting. Some residents enjoy soft music. Maintain a room temperature that is comfortable for the resident. Change bed linens at least daily and keep them free of wrinkles. Reposition the resident at least every two hours. Use positioning devices such as pillows and wedges to maintain a comfortable position.

The resident may fatigue easily. Give rest periods frequently when providing care. Give gentle massages. Provide mouth care and apply lubricant to dry lips. Keep needed items within reach.



Hospice Care

Hospice provides care to people who are expected to live six months or less and are no longer seeking a cure. Like comfort care, the focus is on pain management and support. Hospice also provides counseling and grief support for families.

Hospice workers are specially trained in providing care to the dying. Hospice staff will work with caregivers to provide comfort for the resident and support for the family. Hospice has volunteers who can visit, read to the resident, or bring in music or a pet for the resident to enjoy.

A survey of family members found that they felt hospice services improved the quality of the dying experience for their loved one with cognitive impairment. Medicare, Medicaid, and many private insurance plans cover Hospice services.

Let's review.

1. The last sense to be lost by a dying person is:
 - a) Hearing
 - b) Vision
 - c) Taste

The correct answer is A, hearing. Hearing is believed to be the last sense lost by a dying person.

2. Hospice provides care:
 - a) Whenever a person has a terminal disease.
 - b) When a person has a terminal disease and is expected to live six months or less.
 - c) To people seeking a cure.

The correct answer is B, when a person has a terminal disease and is expected to live six months or less. Hospice services provide comfort and do not seek a cure.

Your Feelings

Have you ever been around a person who was actively dying? How did you feel? Sadness is common. Some people feel uncomfortable. If the person appears to be suffering, you may wish



for a quick, peaceful end. The experience can bring back memories of a loved one who has died. The intensity of your feelings depends on your relationship with the person and your personality. Everyone reacts to death in their own unique way.

Grief

When people learn that they or a loved one have a terminal disease, they begin a grieving process. Dr. Elisabeth Kubler-Ross was a psychiatrist who did extensive studies of people who were terminally ill. She identified five stages of grief:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

Denial

When a person is told that they are dying, they may refuse to believe it. There must be a mistake. Maybe there was a problem in the lab or the wrong results are in the chart.

Anger

They may become angry at God or at the doctor. They often ask, "Why me?" They may direct their anger at their caregiver.

Bargaining

People often try to make a deal with God. "If I can live I will do all I can to help others."

Depression

There are feelings of hopelessness. They become socially withdrawn.

Acceptance

They accept the fact that death is inevitable. They may begin to talk about their death.



People experience these stages in a variety of ways. They do not necessarily go in order. A person may get stuck at a particular stage or experience the same one multiple times. Hopefully, the person will ultimately accept their impending death.

Supporting the Family

Family members may also experience grief. It often begins when they learn that their loved one is experiencing cognitive loss. It is important to remember that this is a difficult time for the resident's family.

A CD player with soft music may be appreciated. The family may wish to bring in some favorite music. Provide comfortable chairs for the family. Offer a recliner, pillows and blankets if they wish to spend the night. Have snacks and beverages available. Be respectful of any cultural or religious practices the family may observe. Ask whether the family would like a member of the clergy to be called.

Many family members have never watched someone die. Their only observations may have been through the media, which is not always accurate. They may be distressed by behaviors or changes in the condition of their loved one. Assure them that this is a normal part of the dying process.

Some family members may want to provide some level of care for their dying loved one. Those who have been part of the resident's physical care may wish to continue. Others can moisten the resident's mouth or massage their hands and feet. Encourage family members to talk with the resident or read a favorite poem or story. They can also share pictures and familiar items with the resident.

Let the family know that you are available if they need anything. A hug or just holding a hand can be comforting. Sometimes family members feel guilty and start to question their end of life choices for the resident. When this occurs, they may need to be referred to a social worker or counselor.

You may be asked how soon death will occur. Avoid making predictions based on past experience. Each person is different. Following the resident's death, it is a nice gesture to send the family a card signed by all of the staff.



Race, Culture, and Ethnicity

Race, culture, and ethnicity can influence feelings about end of life care. In some cultures, the people do not want to be told of their impending death. You may know people who avoid using the words death and dying. They use terms like passing, falling asleep, or departing this life.

Some cultures may have rites or ceremonies that are performed at the bedside of a dying person. Family members may wish to place rosary beads, amulets, or small statues near the resident.

For some, maintaining control is very important. One study found that Hispanic men would refuse pain medication so that they could remain alert. Some people want to die at home while others prefer a facility to avoid being a burden to their family.

Although a person belongs to a certain race, culture, or ethnic group, they may not have the beliefs that are normally associated with that group. It is important that you understand the resident's beliefs and wishes, and respect them, even if you do not agree with them.

After Death Care

Once the resident has died, they should continue to be treated with respect. It is also important to recognize the family's needs at this time. It is helpful to discuss any special needs with the family before the resident dies.

In some cultures families wash the body after death. They may have special clothing or a white shroud. In Jewish tradition, the body is washed and wrapped in white cloth by a group of same sex members of the congregation. Muslims family members wash and position the body in a ritualistic way. Christians may wish to have their clergy come to offer prayers over the body. In one form of Buddhism, monks come and chant. In some cultures, there may be loud, uncontrollable crying. In some instances family members become physically ill.

If the family does not express a desire to wash the body, provide personal care so that the resident appears natural and peaceful. Neaten the room. Allow the family to spend time with their loved one and say goodbye.

Let's Review.

1. Which of the following is a stage of grief according to Dr. Elisabeth Kubler-Ross?
 - a) Rage
 - b) Denial
 - c) Confusion

The correct answer is B, denial. When a person is told that they are dying, they may refuse to believe it.

2. People who belong to a certain race or culture all share the same beliefs. Do you agree or disagree?
 - a) Agree
 - b) Disagree

The correct answer is B, disagree. Although a person belongs to a certain race, culture, or ethnic group, they may not have the beliefs that are normally associated with that group.

3. Mr. Ibrahim has just died. His family tells you that they wish to wash his body. You should:
 - a) Tell them that is your job.
 - b) Tell them it is not permitted.
 - c) Allow them to wash him.

The correct answer is C, allow them to wash him. In some cultures families wash the body after death. They may have special clothing or a white shroud.

4. People react to death mostly in the same way. Do you agree or disagree?
 - a) Agree
 - b) Disagree

The correct answer is B, disagree. Everyone reacts to death in their own unique way.



Advance Directives

Advance directives are legal documents that allow a person to spell out his/her decisions about end-of-life care ahead of time. They give the person a way to tell their wishes to family, friends, and health care professionals and to avoid confusion later on.

Advanced directives include a living will and a durable power of attorney for healthcare. A living will is a document in which a person describes how they would like to be cared for. It states a person's wishes about life-sustaining medical treatment if the person is terminally ill, permanently unconscious or in the end-stage of a fatal illness.

A living will includes decisions about:

- CPR
- Hospitalization
- Tube feeding and IV therapy
- Use of a ventilator
- Dialysis
- Pain management
- Use of antibiotics

A living will is not legally binding; in other words, it does NOT have to be followed. It is simply a guide for those who have to make healthcare decisions when the person is no longer able to do so. Even without a living will, life-sustaining treatment can be stopped if everyone involved agrees. However, without some kind of living will, decisions may be more difficult.

A durable power of attorney for healthcare (also known as a Health Care Proxy) is a document in which a person appoints someone else (known as a proxy) to make medical decisions for them. It goes into effect when the person is unable to make their own decisions. The proxy should be someone who knows the person's wishes and will follow them. Advance directives can help to prevent problems when family members are not in agreement regarding end of life care of the resident.

Maryland Molst (from <http://marylandmolst.org/pages/professionals.htm>)

Maryland MOLST is a portable and enduring medical order form signed by a physician, nurse practitioner, or physician assistant. It contains orders about cardiopulmonary resuscitation and other life-sustaining treatments. MOLST stands for Medical Orders for Life Sustaining Treatment.



A Maryland MOLST form must be completed for all individuals admitted to nursing homes, assisted living programs, hospices, home health agencies, and dialysis centers. It must be completed for certain hospital inpatients being discharged to another hospital or any of the above programs. Any individual who has the capacity to make decisions may ask their physician, nurse practitioner, or physician assistant to complete the MOLST order form to reflect his or her wishes.

MOLST helps to ensure that a patient's wishes to receive or decline care are honored throughout the health care system. In every section of the order form, there are options to accept all medically indicated treatments or to limit interventions. A patient has the right to decline to discuss or make a decision about these topics. If a patient does not limit care, CPR will be attempted and other treatments will be given.

A copy of a completed MOLST form must be given to the patient or authorized decision maker within 48 hours of completion or sooner if the patient is discharged or transferred. Patients must be told they may access the MOLST form in their medical records.

MOLST replaces the Maryland EMS DNR order form and the Life-Sustaining Treatment Options form. The original, a copy, and a faxed MOLST form are all valid orders. If a health care facility or program receives a MOLST order form signed by a practitioner who is not on their medical staff, the MOLST orders are still valid. MOLST orders are valid for EMS providers and all health care professionals, facilities, and programs in Maryland.

MOLST does not change current law or regulations about who has the legal authority to make decisions for an individual who lacks the capacity to make health care decisions. Orders on the MOLST form do not expire. Health care professionals must review the MOLST orders to make sure they accurately reflect the patient's current wishes. MOLST orders may be revised by voiding the current form and completing a new MOLST form.

Let's review.

1. A living will:
 - a) Describes how a person wishes to be cared for;
 - b) Is legally binding; or
 - c) Names a proxy.

The correct answer is A, describes how a person wishes to be cared for. A living will describes a person's wishes for when they are no longer able to make decisions.

2. A Maryland MOLST is:
 - a) A living will;
 - b) A power of attorney;
 - c) A portable and enduring medical order form.

The correct answer is C. Maryland MOLST is a portable and enduring medical order form signed by a physician, nurse practitioner, or physician assistant. It contains orders about cardiopulmonary resuscitation and other life-sustaining treatments.

Summary

Let's review the important points from this part of the program.

- The focus of end of life care is keeping the person comfortable, both physically and emotionally.
- Active dying is a term that is used to describe a person whose body systems are shutting down and who is expected to live only a few days.
- Many changes occur in the body of a person as they are dying.
- Care goals at the end of life may change in level of priority or differ from previous ones.
- The care plan or service plan needs to be reviewed frequently and modified to meet the dying resident's changing needs.
- When a resident is experiencing pain, the focus should be on relieving the pain and not on possible drug dependence.
- Pain is easier to prevent than it is to relieve.
- Your observations may be the only way to determine whether a resident with cognitive impairment is experiencing pain.
- Touching is important to most people, regardless of level of cognition.
- If the resident is unable to respond, it is still important to talk to them.
- Hearing is the last sense to be lost.
- If the resident does not have family members who visit, consider getting a volunteer to spend time with them.
- Remember to not talk about the resident as if they were not there.
- Comfort care is focused on managing pain and other symptoms to keep the resident comfortable and providing support for the resident and their family.

- Hospice provides care to people who are expected to live six months or less and are no longer seeking a cure.
- Hospice staff will work with caregivers to provide comfort for the resident and support for the family.
- Hospice has volunteers who can visit, read to the resident, or bring in music or a pet for the resident to enjoy.
- Medicare, Medicaid, and many private insurance plans cover Hospice services.
- Everyone reacts to death in their own unique way.
- Dr. Elisabeth Kubler-Ross identified five stages of grief: denial, anger, bargaining, depression, and acceptance.
- Caregivers should provide support to family members of a dying resident.
- Family members who are experiencing guilt may need to be referred to a counselor or social worker.
- Race, culture, and ethnicity can influence feelings about end of life care.
- In some cultures families wash the body after death. They may have special clothing or a white shroud.
- It is important that you understand the resident's beliefs and wishes and respect them, even if you do not agree with them.
- Allow the family to spend time with their loved one and say goodbye.
- Advance directives include a living will and a durable power of attorney for healthcare.
- A living will is a document in which a person describes how they would like to be cared for.
- A durable power of attorney for healthcare is a document in which a person names a proxy, someone to make decisions for them. It goes into effect when the person is unable to make their own decisions
- Laws regarding advance directives differ from state to state.
- Maryland MOLST is a portable and enduring medical order form signed by a physician, nurse practitioner, or physician assistant. It contains orders about cardiopulmonary resuscitation and other life-sustaining treatments.

***YOU HAVE COMPLETED THIS PART OF THE TRAINING.
CLOSE THIS DOCUMENT AND RETURN TO THE WEBSITE TO
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REFERENCES:

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