DEFINITIONS

- **Advance Directive** ~ legal document stating a patient's preferences for end-of-life treatment and care
- **Amenity** ~ something intended to make circumstances more pleasant
- **Chronic** ~ long-term
- **Credibility** ~ the quality of being believable or trustworthy
- **Degenerative** ~ relating to a progressive deterioration of a tissue or organ
- **Euphemism** ~ an agreeable or inoffensive expression used to replace one that might offend or suggest something unpleasant
- **Existential** ~ relating to or dealing with existence (especially with human existence)
- **Jargon** ~ characteristic language used by a particular group
- **Liaison** ~ a channel for communication between groups
- **Metastatic Cancer** ~ cancer that has spread from its initial site to other parts of the body
- **Multidisciplinary** ~ involving professionals from more than one specialty
- **Taboo** ~ something excluded from use or mention
- **Therapeutic Interventions** ~ treatment

LESSON 1 ~ INTRODUCTION

OVERVIEW

Death can be frightening. This can be especially true for patients in the terminal stages of chronic disease. These patients often wish for a 'good death.' However, they often fear that they will die alone, in pain, abandoned by their caregivers. Clinicians must provide excellent end-of-life care to all dying patients. In this way, clinicians can:

- Help patients have a 'good death'
- Calm the fears of dying patients
- Support the patient's family

This course will teach you how to provide excellent end-of-life care. You will learn about:

- Palliative vs. Curative Care
- Potential barriers to palliative care
- Guidelines for providing palliative care according to a patient's wishes for a 'good death'
- Guidelines for helping loved ones when a patient is dying

COURSE OBJECTIVES

After completing this course, you should be able to:

- Distinguish between palliative and curative care
- Identify potential barriers to adequate palliative care, as well as methods for overcoming these barriers
- Recognize the key components of a palliative care consultation, including how to meet patient needs in each key area
- List the needs typically associated with the family members of a dying patient, including clinical best practices for meeting these needs

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<tr>
<th>Excellent End-of-Life Care…</th>
<th>Terminally Ill Patients…</th>
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<tr>
<td>Facilitate a good death</td>
<td>Wish for a good death</td>
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<td>Ease pain &amp; fears</td>
<td>Fear pain &amp; abandonment</td>
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COURSE OUTLINE
- **Lesson 1 ~ Introduction:** the course rationale and goals
- **Lesson 2 ~ Curative vs. Palliative Care:** background information on end-of-life care
  - Curative Care
  - Palliative Care
  - Integrated Care
- **Lesson 3 ~ Barriers to Adequate Palliative Care:** information on potential barriers to adequate palliative care
  - Communication failures
  - Bias toward curative care
  - Lack of cultural competence
- **Lesson 4 ~ Addressing the needs of the dying Patient:** specific guidelines for providing palliative care
  - The palliative care consultation
  - Identifying patient needs
  - Meeting patient needs
- **Lesson 5 ~ Addressing the needs of the Family:** practices and guidelines for addressing the needs of the family when a patient is dying
  - Family needs
  - Meeting these needs

**LESSON 2 ~ CURATIVE VS. PALLIATIVE CARE**

**LEARNING OBJECTIVES**
After completing this lesson, you should be able to:
- Distinguish between curative and palliative care
- Recognize key features of palliative care
- List benefits of using palliative and curative care together

**CAUSES OF DEATH: ACUTE VS. CHRONIC**
In 1900, most people died of infectious disease. Death was rapid and certain. Death comes differently in the industrialized world today. Today, about 70% to 80% of all people die later in life. Death occurs due to chronic or degenerative disease. This type of disease is not rapid. Instead, patients experience:
- Slow onset of symptoms
- Gradual decline in health

**CARE OF DISEASE: ACUTE VS. CHRONIC**
When treating acute infectious disease, the goal is to cure the patient. If the cure is successful, the patient recovers. If the cure is unsuccessful, the patient dies. Care of chronic disease tends to be more complex. Remember: Chronic disease has a slow onset and a long course. Therefore, care often has two phases:
- **Cure** ~ in the early stages of chronic disease, the goal is often to cure the patient. Monitoring, diagnostic tests, and treatment are aimed at:
  - Finding the cause of the disease
  - Eliminating the cause, if possible
In some cases, curative care is successful. In these cases, the patient returns to full health.
- **Comfort** ~ in many cases of chronic disease, curative care is not entirely successful. Sooner or later:
  - The patient's health continues to decline.
  - The patient moves into the terminal stages of the disease.
The focus of care then shifts from cure to comfort.
PALLIATIVE CARE

- **Definition** ~ Comfort care for patients near the end of life is commonly called ‘palliative care’. The World Health Organization (WHO) defines palliative care as *an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This is done through the prevention and relief of suffering, with early identification and impeccable assessment and treatment of pain and other problems, including physical, psychosocial and spiritual issues.* On the following screen, let's take a closer look at the who, what, when, where, and why of palliative care.

The following terms may be used interchangeably: Palliative Care, End-of-Life Care, Comfort Care and Symptom Management.

*Note:* This lesson provides an overview of palliative care. More detailed guidelines for providing palliative care are presented in Lessons 4 and 5.

- **What and Why** ~ The goals of palliative care are:
  - To comfort, not to cure
  - To increase quality of life

  Comfort means:
  - Controlling pain and other physical symptoms
  - Treating the dying patient with dignity
  - Respecting the dying patient's cultural beliefs around death and dying
  - Respecting the dying patient's wishes not to receive life-sustaining treatments that do not improve the quality of life
  - Meeting the dying patient's psychological and spiritual needs
  - Meeting the dying patient's social and interpersonal needs

  In short, palliative care treats the whole person. The goal is to give the patient the highest possible quality of life during his or her final days, weeks, or months.

- **Who** ~ Palliative care treats the whole person. Therefore, the care team must be multidisciplinary. Members of the care team may include:
  - Physicians
  - Nurses
  - Pharmacists
  - Social workers
  - Counselors
  - Clergy
  - Physical therapists
  - Occupational therapists
  - Music therapists
  - Art therapists
All healthcare providers should know about palliative care. However, the group most commonly associated with palliative care is hospice. Hospice has a complete range of palliative care services. For a patient to qualify for hospice:
- The patient must have a terminal illness.
- A medical professional must certify that the patient has no more than six months to live.
- The patient must agree to give up all curative treatment.

Hospice criteria:
- Terminal illness
- Less than six months to live
- No further curative treatment

**Where** – A patient may receive palliative care:
- In the hospital
- At home
- At a nursing home
- At a dedicated hospice facility

Hospice can give palliative care in any of these settings. In hospitals and other healthcare facilities, all clinical staff should know how to provide palliative care. This ensures that all patients will have excellent end-of-life care, whether or not they have hospice. Many organizations have developed palliative care teams. They can direct a patient's care and provide expertise about end-of-life issues.

If a patient prefers to remain at home at the end of life, family members may assist in providing palliative care.

**When** – Curative care and palliative care are often thought of separately:
- The WHO definition of palliative care states: *'Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness.'*
- Hospice is an option only in the final stages of terminal disease. Hospice requires patients to give up curative treatment.

However, palliative care practices may be used throughout a patient's treatment. This is true even when the goal of treatment is to cure

**INTEGRATION OF PALLIATIVE CARE**

**Key Elements** – Even when care is focused on cure, it should also give comfort. All care should:
- Manage pain and other symptoms
- Meet the patient's psychosocial needs
- Help the patient have the highest possible quality of life

**Benefits** – When palliative care and curative care are used together:
- Quality of life is a priority throughout treatment, not just near the end of life.
- Patients see that relieving pain and other symptoms is important throughout treatment, not just near the end of life.
- Patients are less likely to see a shift in focus toward palliative care as a sign that healthcare providers have 'given up' on them.
- Terminally ill patients have opportunities to find meaning and closure throughout the course of the disease, not just near the end of life.
- 'Curative' therapies can be used even when palliative care is the focus. For example, 'curative' local radiation may be used in a palliative way to relieve symptoms of terminal metastatic cancer.
Benefits of Integration:
- Maximize quality of life
- Emphasize pain management
- Ease patient fear of abandonment
- Help patients find meaning and closure
- Use curative therapies to provide comfort

SUMMARY
- Chronic disease has a slow onset and a long course. Therefore, care often has two overlapping phases: curative care and palliative care.
- The primary goal of curative care is recovery.
- The primary goal of palliative care is comfort and quality of life.
- Palliative care treats the whole person. Therefore, the care team must be interdisciplinary.
- The group most commonly associated with palliative care is hospice. Hospice has a full range of palliative care services.
- All clinical staff should know how to provide excellent palliative care.
- Curative care and palliative care are often thought of separately. In fact, elements of palliative care should be used throughout treatment. This is true even when the primary focus of care is cure.
- Using palliative and curative care together can have many benefits.

LESSON 3 ~ BARRIERS TO ADEQUATE PALLIATIVE CARE

LEARNING OBJECTIVES
After completing this lesson, you should be able to:
- List three key factors that contribute to inadequate end-of-life care for many patients
- Identify best practices for providing adequate end-of-life care

CURRENT STATE OF PALLIATIVE CARE
All patients should be able to expect excellent end-of-life care. They should expect to:
- Die without unnecessary pain or other physical suffering
- Die according to their end-of-life preferences and treatment decisions

In fact, studies have shown that:
- Many patients have significant pain or other physical symptoms near the end of life.
- Many clinicians do not know whether their patients want life-sustaining treatment near the end of life.
- Many clinicians do not follow their patient's end-of-life treatment decisions.

The way it should be for terminally ill patients…
- Death without unnecessary pain
- Death according to patient’s preferences and decisions

The way it often is for terminally ill patients…
- Significant pain in final days
- Death according to clinician’s preferences and decisions

REASONS FOR INADEQUATE END-OF-LIFE CARE
Why are so many patients receiving poor care at the end of life? Reasons include:
- Failures in communication
- Bias toward curative care
- Lack of cultural sensitivity
Communication Failures
- **What** ~ Patients and clinicians do not always communicate fully. As a result, clinicians often do not understand what patients want and need near the end of life. The clinician may not meet the patient's needs for:
  - Pain management
  - Spiritual counseling

The clinician may give unwanted life-sustaining treatment that:
- Decreases the patient's quality of life in his or her last days
- Prolongs the process of dying
- Increases suffering for the patient
- Upsets the patient's loved ones

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<th>Inadequate Communication</th>
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<td>Misunderstanding of Patient’s Preferences</td>
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<td>Failure to meet patient’s palliative needs</td>
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- **Why** ~ Death and dying are never easy topics to discuss. This is true for both the clinician and the patient. As a result, clinicians may:
  - Offer false hope, instead of giving accurate information.
  - Avoid asking patients what they need and want near the end of life.

When clinicians do not ask, patients may not say what they need and want. Reasons for this include:
- Confusion over unclear information
- Fear or denial of death
- Incorrect belief that the clinician, family, and friends already know what they need and want

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<tr>
<th>When the clinician:</th>
<th>When the patient:</th>
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<td>Offers false hope</td>
<td>Is confused</td>
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<td>Avoids asking questions</td>
<td>Is afraid</td>
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<td>Is in denial</td>
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<td>Assumes his/her preferences are already known</td>
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- **Correcting Failures** ~ Clinicians must understand what their patients need and want. As a clinician, you can find out what patients need and want by:
  - **Improving Communication** ~ certain approaches can help clinicians communicate with patients near the end of life. These approaches include:
    - Begin with open-ended questions. Open-ended questions can help you:
      - Understand the patient's view of his or her illness or prognosis.
      - Identify the patient's values, concerns, and goals for care.
Follow up on the patient's initial responses by asking more questions. Use the patient's own words. This method:
- Shows the patient that you are listening.
- Shows the patient that you understand his or her viewpoint.
- Encourages the patient to share additional concerns, feelings, fears, etc.

Move on to specific questions about palliative care and other end-of-life choices. Ask about:
- Home care vs. hospital care at the end of life
- Use of life-sustaining treatment
- Any specific concerns and fears the patient has shared

Ask direct questions about the patient's symptoms. To give appropriate palliative care, you must know your patient's symptoms. Screen for:
- Pain
- Fatigue
- Shortness of breath
- Symptoms of the illness
- Depression

Screen for spiritual or existential concerns. Clinicians are not always comfortable discussing spiritual issues. However, dying patients often have spiritual concerns. If necessary, refer patients to a religious or spiritual advisor.

Try a less direct approach to screening for distress. Some patients will not give useful answers to direct questions about symptoms and concerns. You may need to take an indirect approach. For example:
- Ask the patient how family members are dealing with his or her illness
- Ask the patient how friends or family members have dealt with a similar illness

Involve the family. Ask the patient for consent to include family members in the conversation. Family members often raise additional issues or concerns.

Make sure all terms are clearly defined and understood. To avoid any misunderstandings:
- Do not use jargon
- State diagnoses, prognoses, and care options clearly
- Define any terms that may be unfamiliar to patients

*Advance Directives* — Patients often do not explain what they need and want near the end of life, because they think that their family, friends, and doctor already know. In fact, family members and physicians often do not know what patients need and want. Therefore, encourage all adult patients to complete an advance directive. This could be a living will or a healthcare power of attorney. An advance directive helps ensure that a patient's wishes for end-of-life care will be respected, whenever the time comes. Advance Directives must be documented in the patient's medical record.

**Bias Toward Curative Care**
- In general, the Western healthcare system has a strong bias toward curative care. As a result:
  * Many clinicians have little experience or training in palliative care.
  * Clinicians may see palliative care as failure. They may think palliative care is the same as 'giving up' on a patient.

This can lead to poor palliative care.

<table>
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<tr>
<th>Clinician bias toward Curative Care</th>
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<tr>
<td>Lack of training in palliative care</td>
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Inadequate Palliative Care
• Correcting the Bias ~ Clinicians must be trained on:
  * The importance of palliative care
  * How to provide proper end-of-life care

Clinicians must understand that many patients value a 'good death.' Many patients do not want 'heroic' use of medicine and technology to prolong life. They would rather have a good death. Therefore, excellent end-of-life care comes back to:
  * Communicating with patients to understand their end-of-life needs and wants
  * Respecting what each patient needs and wants, regardless of any preexisting biases

_The Bottom Line_ ~ Know and respect your patient’s end-of-life preferences.

**Lack of Cultural Competence**

• There are many cultural norms and taboos around death and dying. For example, a patient's culture may:
  * Forbid the use of certain types of life support
  * Dictate that a patient should not be told of a terminal diagnosis
  * Require that a patient die at home
  * Forbid all talk of death or dying. Speaking of death may be thought to cause death
  * Choose a particular family member to make all healthcare decisions for the family

Clinicians must be aware of their patients' cultural norms and values around death and dying. Otherwise, they risk losing their patients' trust. They also risk distressing their patients by:
  * Breaking taboos
  * Providing unwanted or improper end-of-life care

• Improving Competence ~ Clinicians must understand what their patients need and want near the end of life. This requires good communication. To improve communication with a patient from a different culture:
  * Educate yourself about the patient's culture. Use what you learn as a guide. However, be careful not to stereotype the patient.
  * Talk to the patient's family before talking to the patient. Find out who makes healthcare decisions for the family. Find out whether it is okay to tell the patient about a terminal diagnosis. If not, find out who should be informed.
  * Allow the patient to reveal his or her values, beliefs, concerns, fears, and goals for care. Do not impose your beliefs and biases.
  * When necessary, use a medical translator. Translators can be particular useful when discussing end-of-life care. They often know acceptable euphemisms for taboo words and subjects.

• Communicating effectively across cultures:
  * Find out about the patient’s culture ahead of time
  * Avoid stereotypes
  * Interview the family
  * Allow the patient to reveal values, fears, goals
  * Use a medical translator

**SUMMARY**

• All terminally ill patients should expect to die without unnecessary pain. They should expect to die according to their end-of-life preferences.

• Instead, many patients suffer significant pain near the end of life. Many clinicians do not follow their patients' end-of-life preferences.

• Patients and clinicians do not always communicate fully. Therefore, clinicians often do not understand and meet their patients' needs and wants near the end of life.

• Clinicians must be willing to talk about end-of-life issues directly and openly. They must provide accurate information. They also must ask the right questions.

• All adult patients should be encouraged to complete an advance directive.
Clinicians must be willing to put aside their bias toward curative care near the end of a patient's life. They must understand that many patients value a 'good death' over heroic measures to prolong life.

Clinicians must act with cultural sensitivity when providing care to patients near the end of life.

**LESSON 4 ~ ADDRESSING THE NEEDS OF THE DYING PATIENT**

**LEARNING OBJECTIVES**

After completing this lesson, you should be able to:
- List the parts of the palliative care consultation
- Identify the function and goal of each part

**THE PALLIATIVE CARE CONSULTATION**

Good communication is one of the keys to excellent end-of-life care. Communication should be ongoing throughout treatment. This communication does not always need to be highly formal. When a patient nears the end of life, however, a structured palliative care consultation is often a good idea. This consultation should address:
- Prognosis
- Personal goals for end-of-life care
- Physical symptoms
- Psychological, social, and spiritual needs
- Support systems
- Discharge planning

*Note:* The following screens describe a palliative care consultation with the patient actively involved. When the patient is a minor or a non-competent adult:
- The patient's legal representative should be involved.
- The patient's advance directive should be consulted.

### PROGNOSIS

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<tr>
<th>Personal goals for end-of-life care</th>
<th>Physical Symptoms</th>
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<tr>
<td>Psychosocial &amp; Spiritual Needs</td>
<td>Support Systems</td>
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<td>Discharge Planning</td>
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**PROGNOSIS**

Terminally ill patients need accurate information. Accurate information includes an estimate of 'time left.' This information can help patients:
- Make treatment decisions.
- Set goals for end-of-life care.
- Prepare psychologically for death.
- Draw upon support services.

For example, hospice will not provide services unless a patient has a certified prognosis of no more than six months left to live.

*Time Left* ~ Clinicians often do not like to answer the question, 'How much time do I have left?' The answer can never be exact or certain. Remember: *Patients often need and want this information.* Therefore, provide an estimate. Then explain that predictions of 'time left' are always uncertain. This is especially true:
- For prognoses beyond three to six months
- If multiple health factors are involved
- If the clinician making the prediction is inexperienced
- If the prognosis is for a disease other than cancer
End-of-life predictions for cancer patients tend to be most accurate, due to the amount and type of data available.

**Personal Goals for End-of-Life Care**
The patient knows his or her prognosis. The next step is for the patient to decide on personal end-of-life care goals. This often requires input or help from clinicians and family members. The patient may consider goals such as:
- Managing pain and other physical symptoms
- Taking care of psychological, spiritual, or social issues and concerns
- Avoiding unwanted postponement of dying
- Maintaining control over the course of care by completing an advance directive
- Creating a comfortable inpatient environment
- Returning home
- Avoiding future hospitalization

**Maximizing Comfort and Minimizing Burden** ~ In general, end-of-life care goals should focus on:
- Maximizing comfort
- Minimizing burden

Therefore, patients who remain hospitalized may wish to stop routine care such as:
- Monitoring vital signs
- Standard labs and tests

*Note:* For some patients, vitals, labs, and tests may be a burden. For others, this routine may provide psychological comfort. As always, communicate with patients to meet their needs and wants.

For patients who request discontinuation of vital-sign monitoring, pain ‘the fifth vital sign’ should continue to be monitored and charted routinely. This ensures appropriate, ongoing pain management.

**Physical Symptoms**
Managing pain and other physical symptoms is often an end-of-life care goal. End-of-life symptoms should be assessed and addressed during the palliative care consultation. Ask about:
- Pain
- Dry mouth
- Nausea
- Water retention and swelling
- Lack of appetite
- Constipation
- Shortness of breath
- Confusion

*Management* ~ Drugs are used to treat most physical symptoms. In general, opioids are used. Alternative treatments such as relaxation therapy, massage, music therapy and acupuncture also may be used. In some cases, more aggressive treatment options may be available. For example, local radiation can relieve symptoms of terminal metastatic cancer. However, aggressive treatment can have unpleasant side effects. Patients should be fully informed of the treatment options available. They should know all possible risks, side effects, and benefits. This will help the patient make informed treatment and care decisions. Understanding exactly what is causing their symptoms can help comfort many patients.

**Terminal Sedation** ~ Terminal sedation refers to the use of drugs to relieve severe distress in a terminally ill patient. This method is sometimes used to relieve unmanageable physical pain or other symptoms. Patients who request terminal sedation usually have refused life support. Therefore, terminally sedated patients die of dehydration, starvation, or respiratory failure. *US Supreme Court decisions have indirectly supported the legality of terminal sedation. However, the ethics of this*
practice remain controversial. Consult your supervisor or organizational policies for your facility’s position on terminal sedation. Terminal sedation is ethically controversial. Be sure that you understand your facility’s policy on this practice.

**Psychosocial and Spiritual Needs**
Common psychosocial and spiritual issues near the end of life are:
- Anxiety and depression
- Fear or denial of death
- Concerns about finances, especially the financial stability of the patient's family after his or her death
- Wanting to find closure or meaning
- Wanting to strengthen relationships with loved ones

Meet these needs through:
- Discussion
- Referral to a social worker, counselor, clergyperson, etc.

**Support Systems**
Patients near the end of life often fear dying alone. Help the patient think about possible sources of physical, emotional, and spiritual support. These sources may include:
- Family
- Friends
- Coworkers
- Church
- Neighborhood
- Hospital volunteers

With appropriate discussion, planning, and resources, patient care can be arranged to ensure that family members are not unduly burdened.

**Fear of Being a Burden** ~ Patients near the end of life do not wish to die alone. At the same time, they may fear burdening their loved ones. The palliative care consultation should address this fear. It is best to do so with the patient's loved ones. The goal should be to:
- Reassure the patient that his or her care can be arranged in a way that does not create too much of a burden on loved ones.
- Identify resources for family members, for support if and when they feel overwhelmed.

**Discharge Planning**
For inpatients, discharge planning is an essential last step in the palliative care consultation. Various options should be considered, in light of:
- The patient's end-of-life care goals
- The patient's symptom-management regimen
- The patient's need for medical and emotional support
- The family's ability to provide care
- Finances and insurance coverage

Based on these factors, options may include:
- Staying in the hospital
- Transferring to a long-term care facility
- Transferring to a hospice facility
- Going home

**Summary**
- When a patient nears the end of life, a structured palliative care consultation is often a good idea.
- Knowing their 'time left' can help patients set goals for end-of-life care. It can also help them prepare psychologically for death.
In general, end-of-life care goals should focus on maximizing the patient's comfort and minimizing the patient's burden.

Common end-of-life symptoms include pain and shortness of breath. Both can usually be treated with drugs.

Terminal sedation refers to the use of drugs to cause a terminally ill patient to lose consciousness. This method is sometimes used to relieve unmanageable physical symptoms. U.S. Supreme Court decisions have indirectly supported the legality of terminal sedation. However, the ethics of the practice remain controversial.

Meet the psychosocial and spiritual needs of dying patients through discussion or referral.

Dying patients may need help in identifying support systems. They also may need to know that their illness and dying does not create too much of a burden on loved ones.

For inpatients, discharge planning is an essential last step in the palliative care consultation.

LESSON 5 ~ ADDRESSING THE NEEDS OF THE FAMILY

LEARNING OBJECTIVES

After completing this lesson, you should be able to:

- List the needs of a dying person’s family
- Identify clinical best practices that can help meet these needs

PALLIATIVE CARE AND THE FAMILY

The WHO definition states that Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness. This definition recognizes that death does not happen in a vacuum. Instead, death and dying have far-reaching consequences. The patient's family is profoundly affected. Therefore, end-of-life care must consider the needs of the family, as well as those of the patient.

NEEDS OF THE FAMILY

When a person is dying, typical needs of the family include:

- To be with the person
- To be helpful to the person
- To be informed of the person’s changing condition
- To understand what is being done to the patient, and why
- To know the patient is comfortable
- To express their emotions and be comforted
- To be reassured that they have made the right decision (when family members make decisions to withhold or withdraw life support)
- To find meaning in the death of the person

TO BE WITH THE PERSON

When patients die in hospitals or other facilities, staff should encourage and support the presence of family members. If at all possible, the patient should be placed in a private room. This allows the patient to have physical and emotional intimacy with family members. Restrictions on visiting hours should be relaxed as much as possible. Clinicians should be prepared for large groups at the bedside. If the death involves withdrawal of life support, the withdrawal should be planned so that distant family members have enough time to arrive. During withdrawal of life support, distractions and barriers should be removed. Unless it is against organizational policy:

- Monitors should be turned off.
- Leads, cables, and catheters should be removed.
- Bedrails should be lowered.

Consider providing simple amenities. This can help make the family's stay more comfortable. A pager or cell phone can allow family members to leave the bedside briefly, without fear of missing the patient's last moments. Other amenities include:

- Tissues
- Chairs
- Blankets/pillows
- Coffee
- Water
- Telephone

Some family members may wish not to be at the bedside of the dying patient. Be certain to express your respect and understanding for this choice.

**TO BE HELPFUL TO THE PERSON**

Family members often have a strong desire to be helpful to the dying person. This is especially true of parents of a dying child. Allow family members to be helpful by teaching them how to perform:

- Mouth care
- Bathing
- Repositioning
- Assessing pain

Also, encourage family members to bring meaningful personal articles that might comfort the patient psychologically.

**TO BE INFORMED OF THE PERSON’S CHANGING CONDITION**

Clinicians should take the time to explain the process of dying to family members. This should include a clear description of:

- How the patient will die
- What the process of dying will look like

Clinicians often need to anticipate and answer questions that family members are unable to put into words. It is especially important to describe the signs and symptoms of imminent death. These include:

- Decrease in consciousness
- Increase in confusion or restlessness
- Visions
- Changes in breathing sounds or patterns
- Cool or bluish arms or legs
- Inability to respond to touch or sound

Family members often wish to be present in the final moments of the patient's life. Describe the above signs and symptoms to these family members both:

- Before the signs develop
- As the signs develop

This ensures that family members will not leave the bedside at a critical moment.

Family members should be informed about the process of dying. However, avoid making firm predictions about a patient's exact clinical course. These predictions are:

- Difficult to make
- Often inaccurate

When a loved one is dying, family members need to feel the utmost trust in the knowledge, expertise, and competence of the care team. Inaccurate predictions about a patient's death can cause family members to lose trust.

**TO UNDERSTAND WHAT IS BEING DONE TO THE PERSON AND WHY**

All members of the care team should give the family consistent information about the patient's care. In most cases, it is best to choose a single member of the care team to communicate all messages. This helps prevent any mixed messages.

Some clinicians have concerns that communicating with family members violates HIPAA privacy rules. However, this is generally not the case.
A clinician may share information with family members when the clinician believes, in his or her best professional judgment, that doing so would be in the best interest of the patient. This includes communicating that death is imminent.

A clinician may discuss treatment with the patient in the presence of family members or friends as long as the patient does not object.

If consistent with professional judgment, a clinician may discuss an incapacitated patient's condition with a family member at the patient's bedside, or over the phone.

A consent form is not necessary for the clinician to share information for treatment purposes.

TO BE ASSURED OF THE PATIENT’S COMFORT
Clinicians should be able to tell family members that the patient is comfortable. This message should be honest and believable. This requires:

- Ongoing assessment and reassessment of the patient's physical pain and suffering
- Drugs and treatments for relieving pain, to be used as needed

Very close to death, patients may moan or grunt as they breathe. Family members may fear that the patient is in pain. Explain that these breathing patterns usually do not have to do with pain. Provide this assurance even if family members do not ask.

TO EXPRESS THEIR EMOTIONS AND BE COMFORTED
Clinicians often feel the need to ‘do’ or ‘fix.’ One of the most comforting things you can ‘do’ for a dying patient's family is simply to 'be' present at the patient's bedside. Stay with the family. Allow family members to:

- Sit in comfortable silence
- Review the patient's life
- Express feelings of loss and grief

Immediately after the patient's death, be sure to:

- Express your sympathy. 'I'm sorry for your loss' is perfectly adequate.
- Give family members as much time and space as they need to say final goodbyes.

TO BE REASSURED THAT THEY HAVE MADE THE RIGHT DECISIONS
Choosing to withdraw life support can be an agonizing decision for family members. This is especially true if the patient does not have an advance directive. Be certain to address any doubts or guilt by emphasizing:

- The care team shares responsibility with family members for all treatment decisions.
- All decisions were made after giving careful thought to the best interests of the patient.

TO FIND MEANING
After the patient's death, give family members a chance to think about the patient's life. Honor the patient's life and death by bathing and handling the body according to the family's wishes. Be sure to follow any cultural rules or customs. The family's need for support does not end with the patient's death. The family should be given information about anticipated bereavement needs and support networks.

SUMMARY
- A patient's death profoundly affects the family. End-of-life care must consider the needs of the family, as well as those of the patient.
- When patients die in hospitals or other facilities, staff should encourage family members to be present.
- During withdrawal of life support, all distractions and barriers should be removed.
- Allow family members to be helpful to the dying person. This is especially important for parents of a dying child.
- Explain the process of dying to family members. Clearly describe how the patient will die, and what this will look like.
- Do not make firm predictions about a specific patient's clinical course. Inaccurate predictions can lead to a loss of trust, at a time when family members need to feel the utmost confidence in the care team.
- All clinicians should give family members a consistent message about the patient's care.
- HIPAA privacy rules do not necessarily prevent clinicians from communicating with families.
- Clinicians should be able to tell family members that the patient is comfortable. The ability to give this reassurance is based on ongoing pain assessment and use of pain medication as needed.
- Allow family members to express feelings of loss and grief.
- Choosing to withdraw life support can be an agonizing decision for family members. Address any doubts or guilt.
- After the patient's death, give family members the time and space they need to reflect on the patient's life and say their final goodbyes.