

# **Module One**

## **Competency 1**

### **Care of the Person and Family**

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## Competency One

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## Care of the Person and Family

### 1. Communication

When faced with a terminal illness, which there is no curative treatment, we must focus on providing care that supports the underlying patient's and family's values and meanings. Effective communication is foundational to understanding another person's experience. This module provides basic understanding of the essential elements of effective, empathetic verbal and nonverbal communication with patient, family, and healthcare team members about end-of-life issues. The importance of "being present" with another person to communicate effectively will also be explored. Communication issues with dying children and their parents and family will also be discussed.

#### Definitions

<b>Acceptance</b>	Understanding the meaning of the illness within the context of the bio-medical model.
<b>Affective</b>	Relating to, arising from, or influencing feelings or emotions, expressing emotion.
<b>Agitation</b>	Condition of psychomotor excitement characterized by purposeless, restless activity, irritability, crying, pacing or laughing, usually associated with fear and the unknown, extreme emotional disturbance.
<b>Anxiety</b>	Mental uneasiness or distress arising from fear of what might happen, often accompanied by tension, restlessness, tachycardia and dyspnea; an abnormal and overwhelming sense of apprehension and fear often marked by physiological signs (sweating, tension, and increased pulse), by doubt concerning the reality and nature of the threat, and by self-doubt about one's capacity to cope with it.
<b>Empathy</b>	The ability to recognize and to some extent share the emotions and states of mind of another, understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having feelings, thoughts and experience fully communicated in an objectively explicit manner.
<b>Facial Expression</b>	Nonverbal method of communicating information. Actively listening to the patient includes being aware of nonverbal communication such as body position, eye contact and physical distance, as well as language content and style. Facial expressions associated with pain may not be a reliable indicator of the amount of pain experienced by a person.
<b>Intonation</b>	Manner of utterance; specifically, the rise and fall in pitch of the voice in speech.
<b>Intuition</b>	The power or faculty of attaining to direct knowledge or cognition without evident rational thought and inference.

<b>Intuitive Knowledge</b>	Knowing or perceiving by intuition; quick and ready insight; knowledge or conviction gained by intuition: the power or faculty of attaining to direct knowledge or cognition without evident rational thought and inference.
<b>Jargon</b>	Language or terminology peculiar to a specific field, profession or group.
<b>Listening</b>	Also effective, active listening; to pay attention, to hear something with thoughtful attention; give consideration.
<b>Nonverbal Communication</b>	The gestures, movements, and mannerisms by which a person communicates with others. Unintentional transmissions or messages between persons.
<b>Open-ended Questions</b>	Questions which have no yes or no answers; they may be answered in many ways.
<b>Presence</b>	The fact or condition of being present attending to the needs of the patient and family.
<b>Reflective Statements</b>	A statement made by one person which repeats the substance or meaning of a statement made by another person.
<b>Uncertainty</b>	The inability to accurately predict the disease course for individuals.
<b>Values</b>	Relative worth, utility, or importance, something (as a principle or quality) intrinsically valuable or desirable.
<b>Verbal Communication-Language content Style</b>	An act or instance of transmitting; information communicated; a verbal or written message; a process by which information is exchanged between individuals through a common system of symbols, signs, or behavior; a technique for expressing ideas effectively (as in speech).

### Myths

1. Dying patients and families only want to talk about positive things.
2. It is depressing to talk about death.
3. Asking patients questions about dying will remove all hope and they will die sooner.
4. Asking patients and families questions about dying will make them upset and angry.
5. Don't ask patients and families questions about dying unless you can provide the answer for them.
6. Patients and families don't want you to ask questions about dying and loss.
7. Dying patients and their families usually know what kinds of treatments they want and can get them.
8. Treatment of a dying patient should be based solely on the wishes of the patient with family and nurse's concerns minimized.
9. Nurses provide knowledge and support to dying patients and families but have minimal influence on what treatments they choose.
10. Given a choice patients and families will almost always choose life-prolonging treatments.

11. When a patient is dying, there is little nurses have to offer.
12. It is wrong for a nurse to encourage a specific treatment to a dying patient, because the patient should decide for him or herself.
13. Children don't usually know they are dying.
14. Dying children do not experience fear, anxiety, and loneliness like dying adults.
15. Dying children don't know how to communicate their concerns and fears.
16. Dying children don't try to protect and support their parents and siblings.
17. By not answering dying children's questions honestly, you avoid upsetting them.
18. The demands of caring for a dying child are so great that most parents are not able to do it at home.
19. Most dying children prefer to be in the hospital rather than their own home.

### Objectives

- Goal:** - To communicate with patients (adults and children) and families at the patient's end of life.
- To support patients and families as they make decisions regarding appropriate care at end of life.
  - To explore the issue related to patient-centered decision making when dealing with children at end of life.

### Effective Communication

The foundation of understanding another person's experience is effective communication. Communication is an extremely complex task. Professional communication is a skill and like any skill can and must be learned. Communication is needed to establish the therapeutic relationship, obtain relevant information about the problem and discuss diagnosis, prognosis, and treatment options according to the patient's goals to ensure quality end-of-life care.

#### A. Active Listening

Nursing education traditionally has emphasized communication with active listening. Nurses need to ask questions or solicit a comment and then truly listen to responses. Nurses must listen not just to words spoken, but to all other subtle verbal and nonverbal information that is communicated at the same time.

1. *Open-ended Questions:* an open-ended question is the most effective way of beginning to gather information from the patient and family. Asking open-ended questions allows you to understand what issues and information are important to them as well as becoming familiar with their style of communication. In contrast to close-ended questions, which allow yes, or no, or some other fixed response, open-ended questions provide an opening or invitation for the patient or family to tell the story that is important to them.
2. *Reflective Statements:* Given the complexity of communication, reflective statements are a helpful tool in clarifying your understanding as well as the patient's understanding. This is useful in eliciting both facts and feelings. "What

- I heard you just say is, that you want more information regarding pain management before you take morphine. Is that what you intended?" Nurses develop instincts about the meaning of a patient's verbal and nonverbal responses. After being with a patient, they may sense anger or depression. The patient may not have explicitly expressed anger in their words or said they were depressed, but on a "gut" or intuitive level the nurse senses this emotion. Skilled nurses pay attention to such intuitive or tacit knowledge and allow it to guide them in their exploration of the patient and family experience. Be cautious if you sense anger but the person has not used that word to describe their emotion. If you state, "I sense you are angry at this information." The person may feel your reflective comment is judgmental because in fact they were feeling frustrated and not angry.
3. *Clarification*: Sometimes the patient's words are ambiguous or the associations are unclear. If you are to understand their meaning you must request clarification, as in "Tell me exactly what you meant by a cold" or "You said you were behaving just like your mother. What did you mean?"
  4. *Summarization*: Giving a capsule summary of the patient's story at some point in the conversation is a useful technique. It both indicates to the patient that you have been listening carefully and clarifies what you know and what you don't know. "Now, you said you've been coughing for three days, and it's especially bad at night, you are also now bringing up yellow phlegm. You have not had a fever or felt short of breath, but feel congested, with difficulty breathing through your nose. Anything else?" This also allows you, to organize your thoughts in the process of diagnostic reasoning.
  5. *Validation*: Another important way to make a patient feel safe is to legitimize or validate the patient's experience. A patient who has been diagnosed with a life threatening illness, may experience unrelieved distress, you may reassure the patient that the experience is normal by stating something like "I can understand that this diagnosis has scared you, and that is likely why you feel unsettled."
  6. *Reassurance*: When you are talking with anxious patients, it is normal to want to reassure them. "Don't worry. Everything is going to be all right." While this may be appropriate in non-professional relationships, in your role as a nurse this approach is usually counterproductive. Unless you and the patient have had a chance to explore the nature of the anxiety, you may well be giving reassurance about the wrong thing. Moreover, premature reassurance blocks further communication. The first step to effective reassurance involves identifying and accepting the patient's feelings. This promotes a feeling of security.
  7. *Transitions*: Patients often feel anxious and vulnerable. One way to make them at ease is to keep them aware of how you are organizing the flow of the interview, examination, and closing discussion. Sharing this information gives the patient a greater sense of control. As you move from one part of the history to another and through the physical exam, you may orient the patient with brief transitional phrases. "Now I'd like to ask some questions about your past health." Be clear about what the patient should do or expect next. "Now I would like to examine you."
  8. *Being Present*: It is difficult for nurses to be in a situation where all their skills and technology will not change the final outcome of a terminal illness. We are

action orientated, often geared toward helping our patients and families get better. Recent research tells us that as patients and families approach the end of life, we often feel we don't have a role. We withdraw from the patient and family. One of the hardest tasks is to be emotionally present during moments when there is nothing that "can be done." Being a physical and emotional witness to the experiences of another is often all that patients and families need. Accepting the limits of what we are able to do by sitting with the patient and family who have just been informed of a poor prognosis or being in the home of a patient who is deteriorating and attesting to their experience and the unique meaning it has to them, may be all the family and patient expect.

9. *Silence:* Nurses may grow uncomfortable during periods of silence, feeling somehow obligated to keep the conversation going. They need not feel so. Silences have many meanings and uses. When recounting a terminal illness a patient frequently falls silent for short periods to collect thoughts, remember details, or decide whether or not to trust you enough to report something. An attentive posture on the nurse's part is usually the best response, sometimes followed by brief encouragement to continue. During periods of silence be particularly alert to non-verbal cues, such as evidence that the patient is having difficulty controlling emotions. At times patient's silence results from the nurse asking too many questions in rapid sequences or because of insensitivity. Check to see if you have offended them or if you are asking too many questions. Say, "You seem very quiet, is there something I did to upset you?"

## B. Empathetic Statements/Actions

Empathy is defined as the action of understanding, being aware of and sensitive to another without having the feelings, thoughts and experiences fully communicated in an objectively explicit manner. Exhibiting empathy comes naturally to some and is difficult for others. Yet it is a skill nurses should learn and practice. Expressing empathy is part of establishing a therapeutic relationship with a patient and family. As patients talk with you they may express – with or without words- feelings they have not consciously acknowledged. These feelings are crucial to understanding their illness and establishing a relationship. To empathize with your patient you must first identify the patient's feelings. When you sense important but unexpressed feelings from a patient's face, voice, words or behavior, inquire about them rather than assuming how the patient feels. You may simply ask, "How did that make you feel?" When the feelings are expressed, respond with understanding and acceptance. Responses may be as simple as "I understand", "that sounds upsetting" or "you seem sad". Empathy may also be non-verbal. For example, offering a tissue to a crying patient or gently placing your hand on an arm to convey understanding. In using an empathic response, be sure that you are responding correctly to what the patient has expressed. If you have acknowledged how upset a patient must have been at the death of a parent, when in fact the death relieved the patient from a long-standing financial and emotional burden, you have misunderstood the situation.

## Helpful Phrases to Convey Empathy

1. I have seen many people in similar situations and while every one is different I understand something of what you are going through.
2. What are your biggest fears? Worries?
3. Even though we talked and knew this might happen, it doesn't make it any easier?
4. Can you tell me what you are feeling?
5. I wish the news was different.
6. Is there anyone you would like me to call?
7. How are you coping?

### C. Non-Verbal Communication

Each of us sends and receives messages all the time that do not involve the use of speech. Observing patients and families' non-verbal responses can provide clues to their emotions and help nurses convey empathy and support in response. Be alert to such attributes as eye contact, body posture, head position and movement (e.g., shaking or nodding), distance from the patient, and placement of arms or legs, such as crossed, neutral or open. Bringing nonverbal communication to the conscious level is the first step toward using this crucial form of communication.

*Facial Movements:* Do they smile, frown, blush, cry?

*Gaze:* Do they look at you? Look away? How often? Do they stare? Blink a lot?

*Head Movements:* Is their head tilted? Are they shaking it? Nodding?

*Body/Hand Movements:* Do they seem uncomfortable or self-conscious? Do they have difficulty sitting still? Are they wringing their hands? Playing with their purse?

*Posture:* Are they relaxed or uptight? Leaning forward or trying to lean away from you?

*Interpersonal Distance?* Do they seem to be telling you that you are too close?

*Touch:* Do they go to move away when you move to touch them? Do they reach out to you? Seem to look for you to touch them?

*Voice:* Are they having to fight to control? What emotion is expressed in tone, pitch? Are they starting to stutter? Do they have to clear their throat or pause a lot?

### D. Barriers that block Effective Communication

#### 1. Due to Patient and Family Circumstances

In an effort to improve communication skills, consider the following barriers:

- misunderstanding of illness, treatment options and prognosis
- biases over the role of palliative care in society and medical profession
- lack of knowledge of social, cultural norms, roles, and expectations regarding death
- re-alignment of roles within the family structure
- lack of support, lack of coping mechanisms leads to crisis
- physical and emotional depletion
- strong emotions
- differences in values, beliefs or culture

Patients and families may misunderstand the illness and the prognosis. These misunderstandings are more common when the news is bad and, when patients and families are physically, emotionally or psychologically stressed. Information should be given in small chunks and check understanding regularly. Information should be repeated frequently if patient and family not understanding. Also palliative care involvement often signifies imminent death and patients and families do not understand the expertise in palliative care for pain and symptom management that can lead to improved quality of life. Patients and families may never have had a loved one die and therefore lack knowledge of social, cultural norms, roles and expectations regarding death. The confusion over what to do may result in refusal to recognize the severity of illness and prognosis, over-emphasis on treatments leading to possible cure and failure to accept palliative treatment which is seen to mean accepting death.

Faced with the stress of illness and threatened loss, family may struggle to realign their roles within the family structure. They may lack support, may not be able to cope and crisis may ensue. Strong emotions such as anger, guilt, denial over illness, threatened loss or unfulfilled dreams may consume the patient and family and result in inability or refusal to process information. This also can decrease decision-making capacity. Differences in values, beliefs or culture may make it difficult for patients and family to express their emotions, needs and goals with health care providers.

## 2. Barriers due to Nurse's Circumstances

- personal experiences of illness and death
- physical, emotional and psychological stress and depletion
- fears of confronting own mortality and fears of death
- lack of training and poor role models
- fears of emotional outbursts
- fears of appearing weak or unprofessional or displaying emotions
- personal beliefs and values regarding treatment, death, palliative care
- fears of being the messenger
- unrealistic expectations of the success of life-sustaining interventions or failure to discuss role of life-sustaining interventions in view of patient's goals, values and beliefs.
- Inconsistent approach to the issues, differences in language leading to confusion (perception of "mixed messages") and misunderstanding with patients and families.

## 3. Barriers due to circumstances

- lack of previous relationship with patient and family
- lack of privacy
- unavoidable interruptions

### **Patient-Centered Decision Making**

Patients and families living with far-advanced, incurable illness face significant challenges as they make decisions regarding their health care. They are usually novices to the world of illness and medical treatments. Yet they are placed in the medical environment and asked to make urgent life and death decisions. Assisting patients and families to make decisions that are centered on their values and life experiences as well as their disease process is a task that most nurses will face. There is no easy right or wrong answers. Any treatment that causes increased suffering or causes the patient and family to change their values and meaning to accommodate the treatment should be stopped. Accomplishing such patient-centered decision making requires that the patient, family and nurse reach a common understanding of the medical diagnosis and prognosis (reaching consensus). Once consensus is negotiated an initial management plan that is flexible should be established.

When communicating bad, sad or unexpected news, each participant (patient, family and nurse) comes to the experience with his or her own perspective. Having the patient, family and nurse come to a common understanding of the meaning of the medical diagnosis and prognosis is crucial to effective palliative care. Negotiating a common understanding of diagnosis and prognosis is an ever evolving and demanding process. There are three significant issues to consider when negotiating a common understanding.

#### 1. Uncertainty

We never know what will happen to a particular individual no matter how serious the disease. We do not know when someone will die, how they will die or what complications will arise regardless of the diagnosis/prognosis. Many patients/families see themselves as likely to be among the 5% surviving rather than the 95% dying. Helping patients and families understand what their physician is telling them is an important nursing role. Be honest with them. Being informed and truly understanding will allow patients and families to make decisions that are appropriate for their unique personal values and goals.

#### 2. Internal Barriers

Each participant in the discussion carries with them their own internal barriers to understanding and accepting a serious medical diagnosis and prognosis. It is essential for us to understand these barriers to negotiate this common understanding most effectively. Exploring each person's understanding of the illness and its meaning to him or her will uncover the most important barriers. As we care for a patient with serious heart disease over many years, when do we recognize that continued aggressive medical treatment should be replaced by palliative treatments for comfort? Is it after the first ICU admission, or the second or third in the same year or in the same month? Has the primary care provider or a member of the nursing team really communicated to the cardiologist that this patient and family do not want ICU admission one more time? Identifying each person's particular barriers to reaching a common understanding of the diagnosis and prognosis is a central task.

### 3. Acceptance of Diagnosis & Prognosis

Acceptance of the diagnosis and prognosis is a moving target. At first a patient and family deny that this illness is life threatening. Often the patient feels they have tried all the treatments as suggested and therefore should be able to “beat” the cancer diagnosis. As events unfold there will be many opportunities to revisit the diagnosis of a terminal illness and patients and families may begin by accepting that their diagnosis is not curable and opt for palliative care, but along the way decide to treatment a pneumonia aggressively in the ICU because the patient wants to be alive until her daughter’s wedding in two weeks. Accepting that you have a terminal disease is an ongoing dynamic process, which becomes static for a patient, family and nurse only at the time of death. Remember that illness, even a terminal one, is only one small part of personhood.

Many patients already have thoughts and beliefs about what is wrong with them, what their illness is caused by and how serious it is. Asking them what they already know before rushing in with explanations allows you to assess:

- the language they use
- their level of understanding
- any misconceptions, misinformation
- when they were last updated and what they retained
- their emotional state and coping abilities

#### **Sharing Information**

People may ask about “how long” not only to help them make end of life decisions but also because they are verifying that their illness is serious and the end is near. It is better to address prognosis in generalities: days to weeks, weeks to months, or months to years. The intent is not to avoid the question but rather not to give the patient and family false expectations about the length of time remaining.

#### A. Keep it simple and clear

1. Use language appropriate to the level of understanding
2. Pause and wait for reactions after giving information such as:
  - Shock, grief, guilt, fear, anxiety, denial, anger, disbelief, displacement, depression, bargaining, over-dependency, shielding
3. Listen to their concerns, fears, hopes and expectations
4. Be attuned to their emotional responses: verbal, non-verbal cues
  - a. Don’t be afraid of silence
  - b. Don’t abandon
  - c. Don’t make promise
  - d. Don’t give false reassurance
  - e. Recognize the power of non-verbal communication
  - f. Develop a plan with patient and family
  - g. Explore goals, hopes, concerns and fears
5. Acknowledge patients and families’ emotional responses

6. Show empathy and compassion- different from pity(implies they are your inferior) or sympathy (the feeling you have for their response to news, not understanding their feelings)
7. Summarize the imparted information

#### B. Things to Avoid when Sharing Information

1. Talking down to patients and families
2. Avoid Jargon and, if technical term slips out check for understanding
3. Avoid “Why” questions: asks for justification and promotes defensiveness
4. Avoid language you would use with a colleague;
  - a. We almost lost you
  - b. You almost didn’t make it
  - c. You had an arrest
  - d. He is vegetative
5. Avoid euphemisms: growth, tumor, passed away
6. Do NOT say:
  - a. I know what you are going through
  - b. I know this must be a shock YOU DO NOT KNOW
  - c. I know how hard this is

#### C. Helpful Phrases for Addressing Prognosis

- I would like to be able to tell you exactly how long you have left to live but I do not have the power to do so. I can tell you we are likely talking days to weeks.
- We need to hope for the best but plan for the worst. We can’t predict surprises and need to plan in case something happens. We will have a better sense over time as we see how things evolve together.
- I wish I could tell you what will happen but I would not be telling you the truth if I said I could.

#### D. Estranged Family Members/Family from Far Away

Families are often scattered across the country and often appear after having received news over the phone from a variety of other family members and/or friends. Misunderstandings and misinformation are a frequent problem in these situations. These family members may therefore be more anxious. They may feel guilty for not having been closer or for not arriving sooner. They may also feel guilty if there had been pre-existing rifts within the family especially if these rifts contributed to the delay in them being notified of the illness. The distance between them and their sick loved one may cause them to disbelieve or deny the severity of the illness. They will not have witnessed the changes in the patient. They may overprotect and attempt to shield their sick relative in an attempt to make up for being so far away. These family members may have traveled alone and may be isolated from the rest of the family. Distanced from their friends, spouses and children, these family members may be particularly vulnerable to a

lack of support. For all these reasons, when these family members first meet with the nurse there is likely to be a sense of urgency and they might appear demanding. If consent is given for information to be shared with these family members then the nurse must be prepared to discuss in detail the facts of the illness trajectory. It is often beneficial to tell these family members the bottom line first and offer explanation later. It is crucial to ask them what they know before beginning explanation.

#### E. Language Barriers

Use the same approach of effective communication but arrange for a professional translator. It is beneficial if the translator is a health care professional. Tell the translator that their role is to only translate, not to expand on what you have said or to offer their own explanations or interpretations. Emphasize the importance of confidentiality and they should sign the PHIA pledge of confidentiality. Avoid using family members as translators if possible since acting as a translator confuses their role within the family. Sit in a triangle with translator and patient to make it easier to turn to the translator. Give information in short chunks, verify understanding and support emotionally.

#### F. Professional as Patient or Family Member

Medical professionals have an increased need for information. They are therefore often perceived to be difficult or demanding as patients or family members. On the other hand, illness may compromise their ability to think rationally and problems can arise when health care professionals caring for them treat them as colleagues rather than as patients. Seen as a colleague they may not receive the empathy or emotional, psychological support they need as people. Also the professional as a family member caring for a loved one may have difficulty separating their role as professional and family member. For example as the professional nurse they may know that their loved one needs increased pain medication to relieve their pain symptoms, but at the same time realizes that this could lead to sedation or toxicity if not monitored effectively. Unable to monitor the situation themselves because of their overwhelming grief they may become extremely anxious as the dose of pain medication is increased. This is a precarious situation and the nurse must be completely aware of effective communication skills.

#### G. Conflict factors when sharing information

When dealing with end-of-life issues and decisions, nurses face a variety of complex factors: family dynamics, varying beliefs about end-of-life decisions, ever changing health care teams, inconsistent opinions about prognosis, and cultural differences between patients and families and the health care team. When these factors converge, conflict may erupt. Ultimately resolving conflict situations is the responsibility of the health care professional; and understanding the importance of balanced communication, negotiation and mediation will make this job much easier. Due to the fact that the nurse spends more time with the patient and their family than any other healthcare professional, it is often the nurse who deals with conflict resolution. Conflict resolution is time consuming, stressful and often results in lack of and/or over treatment of the patient.

#### Causes of Conflict:

- standards, nature and delivery of end-of-life care
- meaning of life
- quality of life
- multidisciplinary teams with different working cultures
- lack of accepted ethical and legal frameworks
- differences in values and beliefs
- numerous changing health care providers
- cultural differences
- social class and education
- perspectives on choices
- major decisions
- fractured communication
- age differences
- right to make decisions

Conflict and Conflict resolution is time consuming, stressful and often results in lack of or over treatment of the patient. The price of conflict is high because it creates the following:

- intentions interpreted through the lens of hurt, anger and fear
- frustration, tension, burnout and intra-team conflict
- emotional depletion, stress
- loss of personal and professional regard
- decreased confidence in health care system
- complicated bereavement

#### Conflict Resolution

1. Resolution is responsibility of health care providers and is achieved by balanced communication, negotiation and mediation.
2. In order to prevent conflict situations from erupting ask:
  - a. How have you contributed to conflict?
  - b. How has the health care team, system, or environment contributed?
  - c. How can you change your behavior or make a conciliatory gesture?
  - d. Avoid labels e.g. “dysfunctional” or “crazy.”
  - e. Avoid matching anger and arguments.
  - f. Focus on the affective and try to understand the emotional meaning of conflict.
3. Skills for Conflict Resolution
  - a. Create a climate of understanding and change.
  - b. Listen: what has this illness meant to them? (Remember non-verbal)
  - c. Be non-biased.
  - d. Encourage self-awareness.
  - e. Stress the goal= to resolve the conflict.
  - f. Express disinterest in the outcome.

## How to Deal with Conflict

### **To handle conflict among your team members:**

1. Ask those who disagree to paraphrase one another's comments. This may help them learn if they really understand each other. Paraphrase: take another person's comments and reword it into your own words.
2. Work out a compromise. Agree on the underlying source of conflict, then engage in give-and-take and, finally, agree on a solution.
3. Ask each team member to list what the other side should do. Exchange lists, select a compromise all are willing to accept and test the compromise to see if it meshes with team goals.
4. Have each side write 10 questions for their opponents. This will allow them to signal their major concerns about the other side's position. And the answers may lead to a compromise.
5. Convince team members they sometimes may have to admit they're wrong. Help them save face by convincing them that changing a position shows strength.
6. Respect the experts on the team. Give their opinions more weight when the conflict involves their expertise, but don't rule out conflicting opinions.

### **Don't Sweat the Small Stuff... And it's all small stuff**

Many of us spend an enormous amount of time and energy engaged in work. From time to time, most of us must deal with some combination of a variety of unpleasant issues-unrealistic deadlines and expectations, bureaucracies, difficult and demanding bosses, ridiculous meetings and memos, back-stabbing, and criticism, uncertainties, change and rejection. There's no doubt about it: work can be, and usually is stressful.

So how are you going to deal with it? If you choose, you can begin to walk a slightly different path and learn to respond in new, more peaceful ways. I believe that practically anyone can make at least incremental improvements in the quality of his or her life by making small daily changes in attitude and behavior. If you take a step back, you may realize that despite the occasional significant problems in the workplace, much of what bugs us on a day-to-day basis is actually the small stuff.

As you learn to stop sweating the small stuff at work, you'll still have many of the same problems to deal with. However, you'll experience them quite differently. Rather than reacting to each issue with knee-jerk negativity, you'll learn to respond with far more grace and ease. Your stress level will be lower and you'll begin to have a lot more fun.

It is important to distinguish between the little things and the big things.

Little Things:

- you lost your keys
- someone cuts you off on the road
- you have to wait 20 minutes in the grocery store line
- telemarketers call during dinner

Big Things:

- world issues such as violence, hunger, homelessness
- you lost your job
- dealing with an out-of-control teenager
- taking care of a sick or dying family member

**GOAL: To Let Go of the Small Stuff**

**Definition of Success:**

1. Accept that you have options and choices.
2. Welcome accountability for your choices and actions.
3. Respond, rather than react, recognizing your choice point.
4. Recognize that gentle, relaxed people can be super-achievers and successful

What's wrong with worry?

- it's highly stressful
- it's a distraction
  - you anticipate trouble and review past mistakes
  - it becomes difficult to concentrate and focus on positive efforts
- your work suffers and you're launched into a downward spiral
- it's contagious
- Get comfortable with not knowing

**Become balanced, centered, and other-focused**

- recognize personal needs- you can't give from an empty cup
- nurture yourself
- do not focus on others so much that you neglect yourself
- "chunk" your goals – set incremental goals
- recognize your successes
- love and respect yourself

**Which of the following have you done in the past year?**

- Mentored someone at work
- Served on a committee in your organization
- Cleaned up a mess that wasn't yours
- Helped settle an argument
- Stayed late to help a co-worker
- Shared something you know
- Helped fix something broken
- Taught a co-worker how to do something
- Were emotionally supportive to a co-worker
- Surprised someone with a cup of coffee or treat

## Understanding Moods

### Characteristics of Moods:

- your mood is the source of your experience, not the effect
- your mood influences your perceptions of the events
- your mood is always changing
- your life doesn't change much hour to hour, what changes is your mood and your perception of life

### Deal with Low Moods – “This too shall pass”

- avoid over-reacting
- avoid making important decisions
- resist the sense of urgency that often accompanies a low mood
- realize that solutions look just as prevalent in a high mood as problems look in a low mood
- banish thought attacks
- though attacks lead to rehearsing being unhappy, and stressed-out
- over-analyzing results in losing your wisdom and common sense
- allow your thoughts to come to you
  - make space for your thoughts by quieting your racing mind
  - begin to notice when you have a thought attack, and start to catch it earlier and earlier in the process until you can stop it before it gets the best of you
  - become more responsive and less reactive
  - avoid engaging in unnecessary arguments and becoming adversarial
  - reduce self-induced stress

### Show Appreciation for the People you work with:

Employees who feel appreciated	Employees who feel under-appreciated
Happier	No fun to be with
Less-stressed	Sweat the small stuff
More loyal and strive for excellence	Lose enthusiasm for work
Work Harder	Can become apathetic and lazy
Excellent team players	Feel resentful
Exhibit creativity	Easily bothered

When you prejudge, jump to conclusions and criticize unfairly, others will do the same to you. When you see people as innocent and make allowances for their mistakes, they'll do the same for you.

## **Change Your Attitude**

Realize the power of your own thoughts:

If you were to become aware of only one mental dynamic, the most important one to know about would be the relationships between your thinking and the way you feel.

- feeling calm, inspired, in a groove
- ability to keep your composure in the midst of chaos
- capacity to discern true emergencies vs. the small stuff
- being a skilled listener even with distractions
- recognize that mistakes are opportunities to learn
- acknowledge it when there is a problem
- create another plan
- take incremental steps to achieve and maintain balance

Don't let negative coworkers get you down

- increase your compassion
- rub off on them instead of vice versa
- recognize that the problem can be you

Bad days are Inevitable

- chalk it up to your turn in the universe
- accept it calmly and gracefully
- maintain your sense of humor

### **REMEMBER**

Live this day as if it were your last. It might be. The truth is, none of us has any idea how long we have to live. Sadly however, we act as if we're going to live forever. We postpone the things, that deep down we know we want to do.

### **Communication Issues Related to a Dying Child**

Decision-making regarding a dying child focuses on meaningful involvement of the child, parents, and family. However, balancing the parent's view of what is in the child's best interest or with what the child wants can become extremely challenging for the nurse. In our society a heavy responsibility is placed on parents to make decisions for their child, finding ways for the child to participate requires vigilance and skill. Child participation and how it is achieved varies with the developmental level of the child. The discomfort of adults to accept a child's death and adult's wish to protect the child need to be recognized. In addition it is also difficult for the nurse to come to terms with a child's death.

Dying children know they are dying. Children are never too young to know that they or someone close to them is dying. Not acknowledging death creates a barrier between

the child and adult caring for the child. A common fantasy of sick children is that they are responsible for their own illness, so being sick can be interpreted as punishment. Silence only reinforces this misconception. Children need to know they are not responsible for their illness.

To avoid the child feeling isolated and abandoned, sharing information that is cognitively and developmentally appropriate is essential. Dying children experience fear, loneliness, anxiety as well as hope, love and joy just like adults. Acknowledging death and exploring the child's experience allows for the amelioration of fear and loneliness as well as the strengthening of hope, love and joy. Children who choose not to discuss painful matters may be trying to protect their parents and family from further emotional pain.

Like adults, dying children may or may not choose to discuss their concerns but like adults dying children of any age have the capacity to communicate their concerns clearly. How children communicate depends upon their developmental stage. Verbal language must be adapted to a conceptual level and vocabulary that the child can understand. However, children can communicate in many ways other than through speech. Music, art/drawing, drama/story telling, and play are a few of the expressive therapies that can be used for effective communication by and with children.

Children may express their fears, worries or concerns directly, indirectly or symbolically. However they express the question, "Am I dying?" parents and health care professionals must listen closely for it. Once you hear it, you have been chosen by that child to discuss this important issue. Hidden in that question are many others such as: Will you give up on me? Am I going to be in pain? Will I be left alone? Stay with the child to deal with the specific concerns he or she may mention.

This is a letter from a nine year old girl written to the staff on a bone marrow transplant unit. The staff on this unit cared for this little girl for 18 months. Her parents gave permission for this story to be shared.

#### Samantha's Story- A Story of Faith

I've had leukemia since December, 1993. I had been taking chemotherapy and other oral chemotherapy drugs since July, 1995 when I relapsed. We were very unhappy when we heard that news because I only had five more months and then I would have been cured. The doctor advised my parents that I would be inducted into a 35 day program and very intensive chemotherapy, stronger than I had ever been on and then hopefully by then a bone marrow donor would be available. The bone marrow transplant would definitely be the next step, since my system proved to relapse on chemotherapy alone.

January 2, 1996 surgery was scheduled for me. That day I would receive a new central line and a bone marrow tap when I was under anesthetic. The leukemia was in remission the doctor said. For three days my whole body was irradiated. I didn't enjoy radiation at all. My bone marrow transplant day arrived on January 9<sup>th</sup>, 1996. The weather was bitterly cold and there were weather warnings and all kinds of disturbances which caused my family to worry. Well the bone marrow arrived on time. Late that evening, the bag

of the red liquid was hung from my I.V pouring drips into my central line over a period of two hours. Two nurses monitored it while I slept. From time to time I awoke feeling nauseated and trembling. My mom and dad expected a big operation but all that happened was a steady drip. I didn't eat for 33 days but I survived on I.V. fluids. I suffered from mouth sores and sores elsewhere on my bum. They eventually healed. We waited and waited for the bone marrow to begin working.

On day 33 we saw a bit of a rise in the white blood count. I began to eat a soft food diet. Meanwhile my mom and dad and the rest of the family passed the time by helping me create crafts. Day 44 dawned with a shadow of doubt. My counts were not rising so my doctor informed my family perhaps the bone marrow wasn't working. My body needed another bone marrow transplant. I felt really let down. I had followed all my doctor's orders and all the nurse's instructions. We cried and prayed and asked the creator to give me a chance to live the life of a normal girl. I felt I done nothing wrong to deserve a bone marrow rejection. The cyclosporine and stimulating factors drugs were discontinued that weekend.

My sister and family back home on the reserve were informed. They were very sad. My grandmother received a very unique phone call from me. At the time my voice was shaky and weak here in the hospital. My uncle answered the call when the phone rang at Grans. He called gran to the phone telling her it's Sam. Gran was happy to hear from me and asked "is there anything you wish for, when you're in the hospital. I couldn't tell her a floppy eared, dog so I told her, when you come to Winnipeg again can you please bring me one of those new tooneys (\$2.00 coin). This must have been my spirit who contacted my gran because there was no way I could have called long distance to her when I was shakey and weak in my bed. Gran was very puzzled by my call because my family has taught us not to ask anyone for money. Gran happened to have a new tooney which she treasured. The problem was how to get this new coin to me. The weather was freezing cold and gran doesn't like traveling unless she has to. She asked my aunt to bring the coin to me when she was going to Winnipeg. My aunt said, no Sam's asked for you so I'll pay for your bus fare, you can come to the city with me and take that coin to Sam yourself. So Gran packed up her little duffle bag and came to Winnipeg to bring the coin to me. When the coin was handed to me, I wondered how Granny possibly knew I was wishing for one of those coins. I heard that they might be recalled. So Granny told me the story that I've shared with you.

After Granny left that day my doctor came to tell me since my blood counts were starting to rise on their own and another bone marrow transplant was not necessary. A miracle had happened and my Granny who is 74 years old was a part of it. The Creator had answered our prayers we needed to be patient and give the new bone marrow time to work. In the hospital, either my mom or dad or brother stayed overnight with me every night. That's real commitment. I learned to do very good mouth-care. My nurse Darlene even made a video of me doing great mouth-care. For being an excellent patient, I was rewarded from the treasure chest. Nurses from CH4 came to visit me sometimes. What I missed most were children my own age. Because my immune system was very low or non-existent I was not allowed to be around other children, especially my niece and nephew who got chicken pox, measles and live polio vaccine. Although my people were not allowed to visit me, I could feel their good positive thoughts, donations and

prayers that were sent my way. I really appreciate them. Having understanding nurses, doctors, family and friends has helped me through this ordeal. Meigwetch- Thank-you.

Everything mentioned in terms of issues for the dying child apply equally to siblings. The same issues, barriers and needs should be considered with them as well.

ii. For parents and family

As nurses we have an important responsibility to help prepare parents and other family members so they can meet the emotional needs of the dying child. Parents need to know they are doing the right thing when they are caring for their dying child. They are afraid they are not as good at providing care as the nurses. When you as the nurse are with parents, it's extremely reassuring to the parents if you are able to encourage them in their care of the child. Point out things such as; you know what your child likes to eat; you know your child better than I.

### Case Studies

1. Mrs. Gregory is a 62-year old woman who has been a patient for many years at the office where you work as an office nurse. For the past few months, she has complained of increasingly severe upper abdominal pain and weight loss. An ultrasound ordered by the Dr. Minor revealed a mass highly suspicious for primary liver cancer. Mrs. Gregory and Gloria, the youngest of her three daughters, come to Dr. Minor's office to discuss the test results. Dr. Minor discussed the test results, but you were with another patient. You know the family well and expect Mrs. Gregory to understand what Dr. Minor told her, and you plan to instruct her on use of the pain prescription Dr. Minor wrote for her. However, while clarifying her understanding about her illness Mrs. Gregory becomes resistant. She tells you that nothing is wrong with her. She says, "All I need is some herbal remedies to help ease my indigestion." She leaves after agreeing to try the pain pills suggested by Dr. Minor.

Clearly upset with her mother's behavior and attitude in facing a terminal illness Gloria, seeks your advice. She wants her mom to confront her disease and the fact she's dying. However, her two sisters strongly disagree, and tell Gloria they will never speak to her again if she continues to force their mother into confronting her prognosis. How might you respond to Mrs. Gregory's statement, "I don't think anything's wrong" and "I don't want to hear any more bad news?"

Case 2. Mr. Williams is a 53- year old heavy smoker. Seven months ago he had surgery to remove of segment of his lung as part of his treatment for adenocarcinoma of the lung. You're close to Mr. Williams. As his hospital nurse, his family grew close to you, especially his wife, Mary. Weak and thin, Mr. Williams returned home with the surgeon's confident assurances to the family that he would make a "complete recovery". That never happened. Today he was readmitted with distressing symptoms including shortness of breath, severe pain, weakness and anorexia. His body had deteriorated rapidly, showing cachexia. He's even more quiet and frail than you remember. You encounter his family while on rounds. They're visibly upset, but relieved to see a

familiar face. Mary says to you, “He’s really bad and in a lot of pain. None of the doctors are telling us anything.” She asks you to help them figure out what to do.

### Study Questions

Mr. Gurvich is a long time patient at the medical office where you work. Recently he has not felt well. He lost his appetite with a 10 pound weight loss, and is feeling weak. His evaluation by Dr. Duer revealed far-advanced pancreatic cancer. He and his wife were told the diagnosis and just completed consultations with an oncologist and surgeon. Both of the consultants feel they have no beneficial treatments to offer. You are in the room with Dr. Duer as she delivers the latest news to Mr. and Mrs. Gurvick. Dr. Duer leaves and you remain in the room. What first response would be appropriate to use: (Please answer true or false)

1. Ask what Mr. and Mrs. Gurvich understood Dr. Duer to say. T/F
2. Avoid questions about dying, because it will remove hope and upset both the patient and his wife. T/F
3. Say you can not decide for them, they must decide for themselves what to do. T/F
4. Express your concern but in their situation medicine has little to offer. T/F
5. Express your concerns and ask them what goals they wish to achieve in their future. T/F

Amy Reeder is a 4-year-old living with an unusually severe form of cystic fibrosis. Her lungs have been deteriorating rapidly over the past six months and despite aggressive treatments she is getting weaker and requiring ever more frequent hospitalizations. She has two siblings, a 6-year-old brother and 5-year-old sister who are healthy. Her parents, Anne and Jeff, are devoted to her care and can not bear the thought of losing their younger daughter. You are present at a conference Dr. Bret Mayfield, their primary care physician, explains to Anne and Jeff the difficult situation Amy and her family face. There are no good treatments to improve Amy’s situation. After Dr. Mayfield leaves you stay in the room with the parents. It would be appropriate to:

1. Ask Anne and Jeff what they understood Dr. Mayfield to have told them. T/F
2. Assure Anne and Jeff that it is best not to burden Amy with what they have heard. T/F
3. Children should be protected from such bad news. T/F
4. Ask Anne and Jeff how well prepared they feel to provide care for Amy in light of what they have just heard from Dr. Mayfield. T/F
5. Suggest to the family that the parents and child should have a private meeting to discuss such an important conversation. A health professional will just get in the way of meaningful discussions. T/F
6. Suggest that the parents ask Amy to tell a story about what is happening to her or have Amy draw a picture about her experience. T/F

Helen Mussachia is a 30-year-old woman admitted to the hospital with respiratory failure, Mrs. Mussachia has a five year history of Amyotrophic Lateral Sclerosis (ALS) which has left her bed bound. She requires assistance with all activities of daily living (ADLs) and now is having significant shortness of breath due to muscular weakness. Her husband found not breathing. He started CPR and called 911. She is alert, orientated and can communicate. You are in the room while Dr. White, the pulmonary specialist, explains the risks and benefits of a ventilator to Mrs. Mussachia and her husband, Robert. After Dr. White leaves you remain. What first response would be therapeutic:

1. Tell them a ventilator isn't such a hard thing to live with. T/F
2. Ask Helen, "From where do you draw your strength to deal with your illness T/F
3. Ask her husband, "What are your most important concerns?" T/F
4. Reiterate the benefits and risks of the ventilator that Dr. White explained to help them.
5. Ask them what their greatest fears are. T/F
6. Ask them what they would like to happen over the next few days and weeks .T/F

Ed Green is a 17 year old who was involved in a severe MVA on the freeway. He was not wearing his seatbelt and sustained severe lung, heart and abdominal injuries. He has been in ICU for over two months with one complication after another; respiratory failure, peritonitis, sepsis, renal failure, pneumonia, and now heart failure. Despite the best medical care available Ed continues to get worse. Ed is alert and aware of his situation. Even when on the ventilator, which he has just recently come off again, he understands what is happening to him. Everyone has believed in his recovery and provided aggressive curative treatments. You are present in the consultation room when Dr. Ferritto explains to the parents, Lee and Rosie, how serious the situation has become and after Dr. Ferritto leaves, you remain in the room with Lee and Rosie. In your role as a palliative care nurse which is the best response:

1. Tell them not to give up. You have seen similar hopeless cases turn out just fine. T/F
2. Ask Lee and Rosie what they understood Dr. Ferritto to have told them. T/F
3. Make sure Lee and Rosie understand how serious their son's condition is. T/F
4. Ask Lee and Rosie what they think is wrong with their son. T/F
5. Inquire of Lee and Rose thoughts about asking Ed what he thinks is happening. T/F
6. Tell Lee and Rosie they must be strong and not let Ed know how upset they are. If he is aware how bad things are, it will only upset him and worsen his situation. T/F

## Care of Person and Family

### 2. Well-Being

#### A. Spirituality

Spirituality is both concrete and elusive. Spirituality is concerned with the way people live their lives and question the meaning of one's life. Spirituality is often neglected in end-of-life care when the focus is on "heroics". Spirituality helps the dying individual maintain a sense of well-being when faced with physical, perceptual and emotional losses. While holistic nursing care includes the spiritual dimension of well being, this aspect of care becomes a central issue of end of life care. Nurses working with dying persons need to be sensitive to such concerns in their patients and be open to assisting with their explorations. Spirituality offers the individual and family a profound resource for coping with the various challenges of life.

#### Definitions

<b>Religious</b>	Relating to or concerned with religion or spiritual things, especially dedicated to service in a religion.
<b>Self-Transcendence</b>	Is characterized by an increased understanding of self and moving beyond self that is associated with rising above crisis situations such as physical and emotional pain due to ill health, loss and threat of loss. It is often accompanied by a sense of feeling uplifted; a physical lightness, and relief of burden; a closeness to others, to environment and to God; a renewed commitment to life purpose; and an acceptance of inescapable circumstances.
<b>Spiritual Well-being</b>	A sense of inner peace, compassion for others, reverence for life, gratitude and appreciation of both unity and diversity
<b>Transcendence</b>	Of or relating to an order of existence beyond the visible observable universe; especially of or relating to God or a god, or devil.

#### Myths

1. Religion and spirituality are the same entity.
2. A person who does not engage in religious practice is not spiritual
3. Dying people must embrace their religious tradition in order to be able to accept death.
4. Children do not have spiritual thoughts.

#### Objective

**Goal:** To describe the various facets of spirituality and distinguish between spirituality and religion.

### **Distinguishing Between Spirituality and Religion**

To be religious is to be conscious of the connection to an extra-mundane authority that is beyond oneself, beyond one's parents, beyond one's society. Whereas spirituality is thought of as things of spiritual or religious nature, such as of breathing, of wind, or relating to or consisting of, of affecting the spirit. Spirituality has been defined as the quality or state of being spiritual, whereas religion is noted to be a personal set or institutionalized system of religious attitudes, beliefs and practices

### **Stages of Spiritual Development**

The spiritual life is a process, a journey and not a destination:

1. Children have a magical view of life as filled with fairies, demons, superheroes and villains.
2. In the first 12 years, there is transition to a reality base (Is there a Santa Claus?)-shifts from an all-powerful God, who directs everything, to a cause and effect.
3. Dependence, the third stage occurs in adolescence when the individual feels a personal relationship with God who loves the individual unconditionally and serves as an idealized parent. Many adults remain happily at this stage the rest of their lives.
4. Independence- this stage occurs in late adolescence and young adulthood. Spirituality is found within and spirituality and religiosity are differentiated.
5. Interdependence occurs later in adult life. At this stage individuals are open to dialogue between different traditions because they understand that the truth is multidimensional.
6. Few adults achieve the final state- unity. There is the "awareness of oneness of all existence." Individuals at this stage find it easier to speak with "mystics of other religious traditions, who have similar perceptions than to people at other stages within their own traditions who don't.

### **The Spiritual Needs of those with Advanced Disease**

There is consensus in the literature regarding the spiritual needs of individuals who are dying. These spiritual needs include the need for meaning, relatedness, hope and love, the need for meaning and purpose of life, to receive love, to give love, and for hope and creativity. People transcend by:

1. giving to the world creatively through family/significant others, occupation and creative works
2. experiencing the world through receptiveness to others and the environment
3. adopting an attitude of acceptance when faced with a predicament such as an unchangeable situation.

Life never ceases to have meaning for the person because there is always the opportunity to choose the manner in which one faces adversity. From this perspective self-transcendence is both a meaning-discovering and a meaning-giving activity

### The Role of the Nurse

The role of the nurse is not merely to call the chaplain when a patient expresses religious and spiritual concerns, rather it is to listen to the patient in order to help the patient assess how his or her needs might best be addressed. The spiritual issues that arise following the diagnosis of a life threatening illness are abundant and varied. As a person progresses through the phases of an illness (diagnosis, treatment, post-treatment, and active dying) he or she is confronted with mortality, limitations, and loss. This frequently leads to questions “What is my life’s purpose? What does all this mean? What is the point of my suffering? Why me? And is there life after death? It is the role of the nurse to help patients and families find meaning in their suffering in order to enhance the human spirit and foster survival. The purpose of a spiritual assessment is to increase the nurse’s knowledge of the patient’s and family’s sources of strength and areas of concern in order to enhance their quality of life and the quality of care provided. It is essential the nurse shares with information with all interdisciplinary team members. The methods of assessment include direct questioning, acquiring inferred information and observing.

### Case Study

While caring for Dorothy, a sixteen-year-old with recurrent leukemia, she decides that she wants to spend her final days in the hospice so as to spare her younger brothers and sisters the memory of her dying at home. Prior to discharge home from the hospital you have arranged to give her parents a tour of the hospice. At the conclusion of the tour Dorothy’s mother says to you, “of course like us you are Catholic” You reply that you are not. Prior to any further discussion, the elevator door opens and Dorothy and her parents leave. You have the impression that Dorothy’s mother was offended that you were not a practicing Catholic. Do you feel your religion is important in this situation? To whom is it important? Should you follow up on this discussion? If so should the discussion entail religion and spirituality?

### Study Questions

1. All people possess a spiritual nature. T/F
2. A spiritual person is also religious. T/F
3. Spirituality is an approach to the afterlife. T/F
4. Spirituality is concerned with questions of meaning T/F
5. The development of the spiritual component is invariable. T/F
6. By definition, a spiritual person is also religious. T/F
7. Spirituality if an approach to life. T/F
8. There are widely differing views with spiritual needs of the dying. T/F

### **B. Hope**

Hope is an elusive concept. While most of us have experienced it, the place of hope in discussions of far-advanced illness is somewhat problematic for nurses. Hope is usually related to uncertainty or the desire for a reversal of misfortune. The relationship between hope and coping and hope and the illness trajectory are interconnected.

### Definitions

<b>Coping</b>	Management through cognitive and behavioral efforts of specific external/internal demands that are judged as challenging the person's resources.
<b>False Hope</b>	Indicates that a specified outcome is not likely to occur.
<b>High Hopes</b>	Concept usually refers to achievement of some goal; namely, a successful outcome to some venture.
<b>Hope</b>	A desire of some good accompanied with at least a slight expectation of obtaining it, or a belief that if it is obtainable; expectation of something desirable; confidence in a future event.
<b>Hopeless</b>	Giving no ground for hope.

### Myths

1. Once you learn you're terminally ill, hope becomes a contradiction in terms.
2. People with strong religious beliefs are more likely to have unrealistic hopes.
3. Terminally ill persons need to give up hope to truly accept their impending death.

### Objective

**Goal:** To describe the function of hope in patient's lives and the relation of hope to the trajectory of disease.

### The Context for Hope

Four Attributes are associated with hope:

1. The object of hope is meaningful to the person.
2. Hope is a process involving thoughts, feelings, behaviors and relationships.
3. There is an element of anticipation.
4. There is a positive future orientation, which is grounded in the present and linked to the future.

### The Relationship of Hope and Coping

When the level of hope is high, the level of coping is high and vice versa. What are nursing implications of this?

1. Helping patient enhance their coping skills has implications for their approach to the future.
2. Helping patients tap into their religious resources, as appropriate, and to secure the social resources to maintain their performance of role responsibilities is important to the perceptions of coping and hope.

How a person copes also depends on the severity of the illness, the patient's history of coping with stressful life events, and available supports. The nurse needs to assess two important parameters in order to assist the patient in coping in the most functional way

possible; the patient's need for information and need for control in making decisions. Indicators of a person's need for control may include; comfort in asking questions, willingness to assert own needs and wishes relative to the plan of care.

### **The Meaning of Hope in Dying**

Hope is fundamental to the human experience. Hope is intimately bound with suffering. The critical role that hope plays in human life takes on special meaning as death nears. Hope for a cure is destroyed and multiple losses are experienced as many patients continue an illness trajectory that is marked by increasing disability and often pain. As witnesses to suffering and hope, palliative care nurses must understand these complexities and be confident and sensitive in their efforts to address hope and hopelessness in the people for whom they care.

### **Dimensions of Hope**

Dimensions of hope are categorized as; affective, spiritual, relational, cognitive, behavioral, and contextual aspects of hope.

#### **Affective Dimension of Hope**

The affective dimension of hope includes positive feelings such as; joy, confidence, strength and excitement.

#### **Spiritual Dimension of Hope**

The spiritual dimension of hope is associated with spiritual well-being and research has shown that spirituality and spiritual practices provide a context in which to define hope and articulate hope-fostering activities. These activities include; religious beliefs and rituals but extend broader to meaning and the purpose of life, self-transcendence and connectedness with other life-forces. When spirituality is challenged as with a life threatening illness one may feel punished by God and this can lead to hopelessness.

#### **Relationships and Hope**

Relationships with others are an important dimension of hope. Interconnectedness with others is cited as a source of hope in virtually every study and physical and psychological isolation from others is a frequent threat to hope. Hope levels are positively associated with social support. Nurses have a great influence on hope. They can instill faith and hope or they can take it away by distancing themselves showing disrespect especially when information is withheld.

#### **Cognitive Dimensions of Hope**

This dimension encompasses many intellectual and behavioral strategies. Identification of goals can motivate and energize people and thereby increase hope. Active involvement in one's situation and attainment of goals increases the sense of personal control and self-efficacy. The goal-focused thoughts and activities that foster hope are similar to the problem-focused coping strategies. This is because hope is

strongly associated with coping. Diminished hope is associated with poorer quality of life because lower levels of hope are associated with lower levels of self-esteem.

### Case Study

A 30-year-old woman is in a hospital. The palliative care nurse wants to discuss the topic of her fast approaching death with her. She discharges the nurse since she has made it clear she wants to focus her energy on positive approaches and thoughts. Should the nurse address the patient's denial at this point in time.

### Study Questions

1. Facilitating hope for each day is an important contribution to the care of those with far-advanced illness. T/F
2. Hope is a motivating force, an inner readiness to reach goals. T/F
3. Level of religious convictions is related to hope. T/F
4. Devaluation of personhood is a hope, hindering category. T/F

## C. Quality of Life

Quality of life helps us to decide whether life is worth living. How quality of life is defined varies from individual to individual, stage of disease, and also by stage of life. Symptoms, mood states, roles and one's sense of self, all have an impact on quality of life. For instance, therapies that diminish a patient's strength will have a greater impact on the physically active person than the sedentary individual. Well-being is a general term that is presumed to reflect an individual's quality of life.

### Definitions

<b>Quality of Life</b>	Measures difference, at a particular point in time, between the hopes and expectations of the individual and that individual's present experience.
<b>Well-Being</b>	The state of being happy, healthy, or prosperous often in combination.

### Myths

1. There is no "quality of life" once you are terminally ill.
2. Quality of life can be subjectively judged by others.
3. Quality of life is a personal experience to which nurses have no contribution to make.

### Objective

**Goal:** To identify approaches to enhancing a patient's quality of life.

### Quality of Life Determinants

Meaning and transcendence are recognized as important determinants of quality of life. Transcendence implies rising above a set of circumstances. Transcendence also suggests a change in thinking such as, seeing the glass as half empty to seeing it as half full. But it is more than a change in cognition. Meaning and transcendence address how the person views him or herself and being terminally ill. While physical status has an impact, individuals may achieve high quality of life due to other factors that are of significance. In palliative care quality of life is the main focus and it is not about prolonging life but maintaining a good quality of life. There are five components of quality end-of-life care:

- 1) Adequate pain and symptom management
- 2) Avoiding inappropriate prolongation of dying
- 3) Achieving a sense of control
- 4) Relieving burden
- 5) Strengthening relationships with loved ones

### Measuring Quality of Life

In order to measure the quality of life throughout the course of an illness attention must be given to the physical, spiritual and psychosocial needs of the patient and family.

<b>Physical Well-Being</b>	<b>Psychological Well -Being</b>	<b>Social Well-Being (roles)</b>	<b>Spiritual Well-Being (own sense of self)</b>
<ul style="list-style-type: none"> <li>- multiple symptoms due to disease progression, debility, organic, and metabolic changes</li> <li>- ability of self care</li> <li>-pain, nausea/vomiting</li> <li>-lack of appetite</li> <li>-dyspnea</li> <li>-delirium/restlessness/agitation</li> <li>-fatigue/weakness/immobility</li> <li>-sleep changes</li> <li>-GI disturbances (constipation, diarrhea)</li> <li>-Urinary incontinence</li> </ul>	<ul style="list-style-type: none"> <li>- anxiety/fear</li> <li>- depression</li> <li>- loneliness/suffering</li> <li>- dependency</li> <li>- lack of independence</li> <li>- decreased self-esteem and self-respect</li> <li>- guilt/ anger</li> <li>- adjustment to the disease /prognosis</li> <li>- satisfaction with care</li> <li>- despair</li> <li>-acceptance of loss</li> <li>-denial</li> </ul>	<ul style="list-style-type: none"> <li>- sense of burden on family</li> <li>- loss of control over life</li> <li>- relationships with others</li> <li>- changing family roles/status/family structure</li> <li>- family interactions</li> <li>- fear of abandonment/ isolation</li> <li>- financial concern</li> <li>- declined leisure activities</li> <li>- employment status/ workplace relations</li> <li>- sexuality</li> </ul>	<ul style="list-style-type: none"> <li>- religion (rituals, practices, prayers, mediation)</li> <li>- relatedness to God</li> <li>- meaning of life / existential (reason for events, purpose of life, belief in a primary force in life)</li> <li>- hope (realistic-based)</li> <li>- forgiveness</li> <li>- transcendence (redefines views of life, redefines relationships)</li> <li>- spiritual needs vary and fluctuate with changes in physical symptoms</li> <li>- feelings of uselessness</li> </ul>

The importance of having items that are relevant to the patient and family must be identified and instruments used to measure these variables of quality of life must not pose as a burden to the patient and family. Measurement of quality of life is undertaken as an outcome measure of care for quality assurance. Quality of life is what the patient determines is important. Enhancing quality of life enables the patient to die well.

### Enhancing Quality of Life

Nurses play a major role in enabling terminally ill persons to die well. There are a number of ways to enhance quality of life at the end-of-life:

- effective communication/listening
- stress management/effective coping mechanisms
- available resources/support available
- support in decision making
- resolve conflicts
- complete unfinished business
- maintain “non-illness” related aspects of life
- changing perception of space, span, or focus of time (take one day at a time)
- define attainable goals
- engage in spiritual practices
- help the individual explore losses and their meanings.

These activities focus on resolution of past problems, adjustment to illness related factors, reorganization of current activities to more effectively meet demands, and exploration of non-medical life enhancing practices. In addition to these suggestions, the importance of attention to symptom management cannot be emphasized enough. Finally helping a patient recognize the legacy that he or she is leaving contributes to quality of life.

### Case Study

Mrs. O’Leary greeted you, the palliative care nurse, early one morning with, “Where’s my drink?” Taken aback, you repeat, “Where’s your drink?” Mrs. O’Leary replied, “Yes! with a little something in it!” What is the best response:

1. “We don’t allow liquor in the hospital” Yes/No
2. “Why would you ask for a drink in the hospital” Yes/No
3. “Maybe your family can get you something.” Yes/No
4. “It sounds like you’d like a party” Yes/No

### Study Question

1. Quality of life is not significant in illness care T/F
2. Quality of life is invariable for all persons T/F
3. Physical factors are the key determinants of quality of life T/F

## **D. Suffering**

Although some people may assume that pain and suffering are inevitably associated, this is not true. Although there is a link between pain and suffering, they are distinctive entities. The sense that pain and suffering are intertwined does violence to considerations of both pain and suffering.

### Definition

**Suffering**      The state of severe distress associated with events that threaten the intactness of the person.

### Myths

1. If you alleviate a patient's pain and other physical symptoms, then you will alleviate suffering at the end of life.
2. Suffering is inevitable at the end of life.

### Objectives

**Goal:** To describe the multiple causes of suffering and distinguish between suffering and pain.

### The Distinction between Pain and Suffering

Pain may occur without suffering. Such pain is very often short-term. The pain associated with suffering is usually of longer duration but may occur without suffering. Suffering may also be experienced without physical precursors. Pain hurts physically whereas suffering may hurt physically but is accompanied by psychosocial and spiritual effects.

### The Amelioration of Suffering

There is no excuse for not relieving pain. Excellent pain relief is a necessary part of excellent end of life nursing care. Given that suffering has to do with a threat to the integrity of the person, the approach to relief is not technological. The approach is one of listening and learning about the patient as a person. What is meaningful to them or what is not. It has to do with presence. Being there for the person as he or she grapples with the reality of death is the most successful way to alleviate the suffering. The relief of suffering brings to bear a holistic approach to patient care. This holistic approach acknowledges the patient as person and the caregiver as person. The role of the nurse is to be present and accompany the patient as person through the illness trajectory.

### Case Study

Mr. Brown is a 32-year-old white male who is married and the father of two little girls, 5 and 7 years of age. An architect, Mr. Brown is hospitalized with acute leukemia. The chemotherapy has left him sick and exhausted. Moreover, he has been told by his doctor that they want to try another regimen in order to get him into complete remission. When Mr. Brown attempts to obtain more information about his situation, an intern tells him that unless he tries the new regimen he will die and even if he does, there are no guarantees. At this point his wife and young children come bounding in. Sarah, his 5-year-old begs him to get well so that he can see her in the Christmas concert. She tells

him all other fathers will be there. After his family leaves, Mr. Brown wonders why he went to night school and worked so hard to become an architect. A child of the inner city, Mr. Brown worked days and went to school at night. Marrying his high school sweetheart, he promised his wife when his oldest daughter was born that she could stop work and stay home to care for their family and he would earn a living that would take care of all of them. The thought that he would not be able to keep his promise, nor be able to attend Sarah's Christmas concert, was more than he could bear. You come into Mr. Brown's room and see him slumped over in his bed. It would be appropriate to:

1. Leave the room and come back when Mr. Brown is perkier. Yes/No
2. Straighten him up in the bed so that he breathes easier. Yes/No
3. Comment that he seems to be in deep thought. Yes/No

### Study Questions

1. Meaningful pain is indicative of a degenerative process T/F
2. Suffering is an affliction of the body not the person. T/F
3. The relief to suffering is:
  - a. Technological,
  - b. Psychosocial
  - c. Spiritual
  - d. Psychosocial and spiritual
  - e. Multifaceted
4. There is no such thing as meaningful pain. T/F
5. Where there is pain there is always suffering. T/F
6. There is no relief for suffering- it is inevitable. T/F

## **E. Psychosocial Care**

Psychological factors are the human responses to the challenge confronting individuals in their everyday lives. The manner in which the individual responds to everyday occurrences may provide a clue as to the response to far-advanced disease. A variety of psychological effects such as fear and depression have an impact on psychosocial well-being. While these effects result from the stress of illness, they also have an impact on the illness trajectory itself. For example, the individual who denies medical findings of disease and thus forgoes medical therapy may have a more rapid downhill course of illness. Psychological factors are important facets of living and dying. The presence or absence of psychological factors has an influence on well-being and quality of life.

### Definitions

- Denial** An unconscious defense mechanism characterized by refusal to acknowledge painful realities, thoughts or feelings.
- Depression** a psychotic or neurotic condition characterized by an inability to concentrate, insomnia, feelings of extreme sadness and hopelessness.

<b>Fear</b>	A feeling of agitation and anxiety caused by the presence or imminence of danger. A feeling of disquiet or apprehension.
<b>Psychological Well-Being</b>	Seeking a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities, and fears of the unknown, as well as positive life changes.
<b>Psychosocial</b>	Involving both psychological and social aspects.
<b>Resignation</b>	Unresisting acceptance of something as inescapable; submission. The state of being resigned or submissive; quiet or patient submission; unresisting acquiescence, as, resignation to the will and providence of God.
<b>Withdrawal</b>	The act or process of withdrawing, detachment, as from social or emotional involvement

### Myths

1. All dying person progress through the five stages outlined by Elizabeth Kubler Ross.
2. The goal of care for persons with advanced terminal diseases is helping them to get to the stage of acceptance
3. It's a waste of time to help terminally ill people resolved their psychosocial issues.
4. Children do not realize they are dying.

### Objective

**Goals:** to incorporate psychosocial aspects of care into planning for the patient and family.

### Psychological Well-Being

Psychological well-being is seen as seeking a sense of control in the face of life-threatening illness characterized by emotional distress, altered life priorities and fears of the unknown, as well as positive life changes. In order to promote psychological well-being two questions must be asked:

1. What do patients worry about?
2. How do they cope?
  - i. What do patients worry about?
    - i. Further debilitation and dependency
    - ii. Pain and Suffering
    - iii. Consequences for dependents and arranging affairs
    - iv. An uncertain future
    - v. Lingering
    - vi. Dying alone
    - vii. Loss of control

- viii. Changing relationships
- ix. Existential concerns
- x. Change in mental function
- xi. Afterlife

ii. How do they Cope? (Psychological Effects)

1. Denial: denial can be beneficial in the short term if it enables the patient to sustain his or her integrity and personal freedom. The denial must be respected if that is his or her method of coping. However, denial can interfere with taking care of affairs.

2. Fear and Anxiety: fear and anxiety are common psychological responses to end-of-life. Fear is the response to perceived danger, whereas anxiety is a non-specific response. Terminally ill persons may experience both of these responses together or separately. Children also worry about how their parents and families will go on living without them.

3. Anger: anger is a healthy and understandable response to the numerous losses (future, unfulfilled promises, shattered dreams, and ended relationships). Anger that is expressed may be difficult for family members and nurses to accept. Being clear as to the reason for the anger whether it is related to terminal status or for some other reason will help family members and professionals to respond in a productive way. A positive nursing response is to demonstrate respect and empathy.

4. Depression: depression is the most frequently observed symptom in the terminally ill. Indeed it has been observed in 77% of persons with far-advanced cancer. Clues to the diagnosis of depression in the terminally ill are lack of pleasure, hopelessness, helplessness, powerlessness, worthlessness, social withdrawal and isolation, guilt, and suicidal ideations

5. Acceptance, Resignation and Transcendence: acceptance is acknowledging the inevitable finality of human life, though not necessarily liking it. The polar extremes of acceptance are resignation and transcendence. With resignation, the individual experiences a sense of hopelessness to a situation that cannot be changed. Transcendence, on the other hand, indicates acknowledging the situation but rising above it to achieve an integration on a higher level. Transcendence integrates the psychosocial with the spiritual aspect for the terminally ill person.

Understanding the patient's world as he or she perceives it will enable the nurse to explore the possibilities that are in keeping with the patient's view of the world. People die as they have lived. It is not a realistic goal to try and change the personality of the patient or inhibit their coping responses to the situation. In addition nurses cannot change family dynamics during an advanced progressive illness at end of life.

### **Factors Influencing the Risk of Psychological Morbidity**

Nurses must also be cognitive of others factors that contribute to the risk of psychological morbidity.

#### **Possible Factors Influencing the Risk of Psychological Morbidity**

Area	Factors
Physical Issues	<ul style="list-style-type: none"> <li>- stage of illness, particularly advanced stage</li> <li>- type of illness</li> <li>-functional limitations</li> <li>-physical symptoms, particularly pain and weakness</li> <li>- anorexia/cachexia syndrome</li> <li>-neurological dysfunction such as difficulty concentrating, dysphasia</li> <li>-endocrine disturbances</li> <li>- organic psychological disturbances such as delirium/depression</li> <li>-changes in body image</li> </ul>
Psychological and Family Issues	<ul style="list-style-type: none"> <li>- previous psychiatric history and family dysfunction</li> <li>- individual and family coping strategies</li> <li>-substance abuse</li> <li>-family abuse and violence</li> <li>-unresolved grief</li> <li>-post-traumatic stress disorder</li> <li>-lack of preparation for death</li> <li>-spirituality</li> </ul>
Treatment Issues	<ul style="list-style-type: none"> <li>- medications including opioids, chemotherapy, corticosteroids</li> <li>- dependence on life support machinery or other aids</li> <li>-radiotherapy</li> <li>-multiple physician care providers with lack of coordination and/or communication</li> </ul>
Social Factors	<ul style="list-style-type: none"> <li>-socioeconomic status</li> <li>-financial issues</li> <li>-culture and ethnicity</li> <li>-religion and/or belief system</li> <li>-family history of illness</li> <li>-lack of supports</li> <li>-availability of medical support services such as palliative care, home care or other components of health care.</li> </ul>

#### **Case Study**

Jimmy, a young boy whose mother was dying, wanted to let his mother know he was thinking of her. His mother, who had been diagnosed with recurrent leukemia, had been moved to the Intensive Care Unit (ICU). Jimmy made a drawing for his mother. Since the family home was three hours driving distance from where his mother was hospitalized, Jimmy gave the drawing to his father to bring to the hospital. You are the

palliative care nurse. What is the best approach from a palliative care perspective to do with the picture?

1. Keep the drawing outside the patient's room as it may contain pathogenic bacteria, dangerous to the mother's health. Y/N
2. Keep the drawing outside the patient's room as the mother is unconscious and can't see it anyway. Y/N
3. Send the drawing back with the father as a persona items aren't permitted in the ICU. Y/N
4. Tape the drawing to the wall. Y/N
5. Tape the drawing to the wall and talk with the mother about the lovely drawing Jimmy made just for her. Y/N

### Study Questions

1. Psychosocial factors are critical to quality of care at the end of life. T/F
2. Stressors describe events that have the capacity to induce emotional distress. T/F
3. Adjustment to disease has an impact on psychological well-being. T/F
4. Fear is the most frequently observed symptom in the terminally ill. T/F

## F. Culture

Developing the ability to interact with patients of many backgrounds should be lifelong professional goal. Each of us has a culture. It is the learned values, beliefs, norms and way of life that influences an individual's thinking, decisions and actions in a certain way. Culture has been characterized as a way of life, a way of viewing things and how one communicates. It provides an individual with a way of viewing the world, as a starting point for interacting with others and reflects the assumptions individuals make in every day life. Culture is a strong determinant of people's views of the very nature and meaning of illness and death, of how end-of-life decisions can or should be controlled, how bad news should be communicated and how decisions should be made. When patients and nurses have different cultural backgrounds, they frequently follow different "maps" which can hinder effective communication.

### Culture- Everything About You

The Way You Live	The Way You View Things	The Way You Communicate
Customs, habits, traditions	Beliefs, Values	Meaning of Language
Food and Its Meaning	Spirituality	Interaction Pattern
Music, Clothing	Health Beliefs	Verbal and Non-Verbal
Religious Practices	Perceptions	
Health Practices	Attitudes	
Child Rearing	Expectations	
Family Structure		
Relationships		

Culture is influenced by age, gender, education, life experiences and sexual orientation. Social and economic status, race, language and ethnicity also influence culture.

#### Cultural Considerations for End-of-Life Nursing Care;

- no one has more culture or less culture than anyone else
- what we consider to be “common sense” is determined by culture
- culture is passed from generation to generation without being articulated
- it is inaccurate to believe that if we do not participate in our cultural traditions we are not affected by them
- our cultural background has a significant influence on our clinical practice
- the first step in effective cross-cultural work in health care is to understand our own cultural values and beliefs.

#### Questions about families’ cultural perspectives in end-of-life care:

1. Does the patient/family have a purely biomedical view of illness?
2. Does the patient/family believe this illness should be controlled and the timing and nature of death can be influenced?
3. Does the patient/family value individual decision-making? Or collective?
4. What personal/cultural beliefs does this patient/family hold about critical illness and death?
5. Do I understand how this patient/family perceives the cause and nature of this illness?
6. Do I understand how this patient/family perceives the nature and meaning of death?
7. Are there any death-related rituals or observances they wish to honor or perform?

#### Case Study

A 16-year old Aboriginal high school student from a lower socioeconomic urban community comes into the emergency department at a local hospital because of abdominal cramps. The nurse a 30- year old European from a middle-class suburb, asks many questions and reflects incorrect assumptions. “So are you planning to finish high school? What kind of birth control do you want? The teenager feels pressured to accept birth control despite stating clearly that she had not had intercourse, and didn’t plan to until she was older, and married. She is an honor student and athlete planning to go to graduate school, but these goals are ignored. The issue of cramps is given little attention by the nurse. “Oh, you can just take some ibuprofen. They usually get better as you get older.” The patient will not take the birth control pills that were prescribed nor will she seek health care soon again. She has experienced ineffective health care due to cross-cultural misunderstanding and clinician bias. Give a similar example in relation to an end-of-life situation?

#### Study Questions

1. Culture is a system of shared ideas, rules and meanings. T/F
2. Values are standards we use to measure beliefs and behaviors. T/F
3. Biases are the attitudes or feelings we attaché to the awareness of differences T/F
4. Being aware of our own biases and values, will give you the right answers T/F

## Answer to Study Questions – Competency One- Care of Person and Family

### Communication

**Case Study One:** Mrs. Gregory (62- complaining of upper abdominal pain- diagnosed with primary liver cancer). She tells you nothing is wrong with her and she does not want to hear anymore bad news. How might you respond?

#### Effective Responses:

**Empathic:** I can appreciate that this discussion has been difficult.

**Reflective:** I'm confused because I just hear you say two different things; that you don't want to hear any more bad news and also that you don't think anything is wrong.

**Open-Ended** Could you share with me more about what you are thinking so we can work together.

**Case Study Two:** Mr. Williams( 53 – condition is rapidly deteriorating).  
How do you respond to family's concerns.

#### Effective Responses

1. Help me understand what you mean by "It's really bad."
2. Share with me what the doctor has told you so far.
3. It sounds as if you both have been having a rough time. Mr. Williams, what are your concerns?
4. I'm glad I'm here too. I'm going to work with you to help your dad. Let's start with your helping me to understand exactly what your concerns are.

More effective responses employ features that help avoid the premature closure of communication.

#### Study Questions

A. Mr. Gurvich- far-advanced pancreatic cancer

1. True
2. False – for effective communication with patients, including people facing the end-of-life transition, the first and most basic skill we need to develop is that of listening. We ask questions or solicit a comment and then truly listen for the response- not just to words spoken but to all subtle verbal and nonverbal information that is communicated.
3. False- The foundation of understanding another person's experience is effective communication. Before you can offer meaningful support you must first gain understanding of the patient and family experience or story.

4. False- too early for this reply need to understand what are their goals and values first.
5. True

B. Amy Reeder- severe form of cystic fibrosis

1. True- open-ended questions to better understand what these patients have heard in talking with the doctor is an essential first step in supporting them during this difficult time.
2. False- Dying children experience, fear, loneliness, anxiety as well as hope, love and joy just like adults. Acknowledging death and exploring the child's experience allows for the amelioration of fear and loneliness as well as the strengthening of hope, love and joy. Silence reinforces misconceptions, isolation and limits the sharing needed to cope with overwhelmingly difficult experience for everyone. In fact, many children who choose not to discuss painful matters may be trying to protect their parents and family from further emotional pain.
3. False- see above
4. True- As healthcare professional we have an important responsibility to help prepare parents and other family members so they can meet the emotional needs of dying child. Parents need to know they are doing the right thing when they are caring for their dying child. They are afraid they are not as good at providing care as the nurses and physicians in the hospital provide. When you as the nurse are with the parents, it's extremely reassuring to the parents if you are able to encourage them in their care of the child. Point out the simple things: you know what your child likes to eat; you know your child likes a red popsicle rather than a yellow one; you know which book is your child's favorite.
5. False- They have asked for your help.
6. True

C. Helen Mussachia- ALS

1. False- When a patient is experiencing advanced, incurable disease for which there is no effective treatment, what is good healthcare? Many palliative care professionals would answer this question in the following way. When faced with a situation, for which there is no curative treatment, we must focus on providing care that supports the patient's and family's underlying values and meanings. Anything we can find in our treatments that support the patient and family to live in a meaningful way consistent with their values is "good healthcare." "Bad healthcare" is when we do things that increase patient and family distress and force them to adapt or change their meanings to endure the medical treatment. Thus, before the members of the healthcare team start treatments we must first understand our patients and families as unique humans, unlike any others. It is in the richness of understanding diverse human experience that "good" care is provided by professional caregivers at the end of life. The foundation of understanding another person's experience is effective communication. Thus,

- reassuring Mr. and Mrs. Mussachia that a ventilator is something which they can adapt is premature until you have explored their illness experience more deeply.
2. True- An open-ended question is the most effective way of beginning to gather information from the patient and family.
  3. True- Another open-ended question to explore the husband's understanding of the situation.
  4. False- First start with understanding the patient and family's goals and wishes. Building a common understanding about life-threatening illness among the patient, family and healthcare professional is an essential early step in the long process of living with illness. Even as this understanding of the diagnosis and its meaning is being built, the question arises, "What do we do next?" There are many possible approaches to terminal disease. Reaching a consensus about a plan – an initial management plan- can be more daunting than understanding the meaning of the disease itself. What direction should this initial path take? When faced with diseases such as advanced cancer or end-stage heart disease, for which we have no effective curative treatment how do we know where to go? There is no easy or absolute answers. The correct path is one that most closely reflects the values, attitudes and ultimately the goals of a patient and family. As a nurse you have an important opportunity to help the patient and family chart a management path that will best meet everyone's needs by uniting medical technology with personal values.
  5. True- The patient and family likely feel frightened and disoriented by the course of the illness and the future. This new future must recognize impending loss of function and a sharply limited time horizon with a finite end point. Asking an open-ended questions at this point is extremely important.
  6. True- The understanding provided by the answer to this question is the foundation upon which the future of the patient, family and health care professionals will be built.

#### D. Ed Green- MVA accident

1. False- Healthcare professionals often find it difficult to tell parents that there is no longer any effective cure-orientated treatment. However, if the parents can be supported to ask the care provider if it is time to stop cure-orientated treatment and move to comfort (palliative) care, most providers will share a more honest appraisal of the medical situation. The key for the nurse is to recognize the pivotal role of encouraging and supporting parents in expressing their true feelings, concerns and goals.
2. True- an open-ended question is the most effective way of beginning to gather information from the parents.
3. False- The best way to help the parents is to understand what the doctor just told them it is not to repeat the same information just provided. Instead it is better to find out what they have heard and understand.
4. True- Parents find it hard to accept the death of a child. The parents cannot fulfill their parental role regarding end-of-life decisions if they do not understand the grave nature of the illness.

5. True- Adolescents may want to be very much involved in the decision as whether to continue or stop curative treatment. All children should be allowed to meaningfully participate in such decisions based upon their developmental level and using conceptualizations and vocabulary consistent with their stage of development.
6. False- Research has shown that early discussions of hospice care between clinicians and parents were associated with greater likelihood that parents would describe their child calm and peaceful during the last month of life. Active involvement of caregivers committed to palliation may reduce the suffering of dying children. In addition, when aggressive cancer-directed therapy is begun with a child whose long-term survival is low, simultaneous attention to palliative may be appropriate.

### **Well-Being**

#### ***Spirituality***

E. Dorothy- 16 year old with recurrent leukemia

1. True- all people possess a spiritual nature
2. False- not all people are religious
3. False- spirituality is for the living
4. True- spirituality helps people to question the meaning of life.
5. False- development of the spiritual component is variable
6. False
7. True
8. False

#### ***Hope***

F. 30 year old woman – who is approaching death.

1. True
2. True
3. True
4. True

#### ***Quality of Life***

G. Mrs. O’Leary, “Where’s my drink?”

1. This answer may be right or wrong what is significant is that it closes off discussion, therefore making it wrong.
2. No- this response places the patient on the defensive
3. No- while a possibility, it doesn’t allow for further discussion about what this lady really wants.

4. Yes- this option interprets the literal statement by patient into a symbolic statement.

### ***Suffering***

H. Mr. Brown wonders if his life has been worth it all.

1. No- this is not therapeutic.
2. No- it is not his physical symptoms that need addressing.
3. Yes- commenting that he seems to be in depth thought is a neutral opening statement that allows you to ascertain whether he might be ready to talk at this time.

Study questions

1. False
2. False
3. e
4. False
5. False
6. False

### ***Psychosocial Care***

I. Jimmy's mother is not responsive and he brings her a picture.

1. No- while it is true it is no longer relevant in this case.
2. No- also may be true but it breaks faith with a young boy who wants his mother to be aware of his love for her.
3. No- sending it back shows a lack of judgment by the nurse and a lack of discretion.
4. No- step in the right direction but mechanistic
5. Yes- adds the nurse's caring to the situation. Given that hearing is often one of the last senses to be lost, the nurse can relate Jimmy's vision of reaching out to his mother.

Study Questions

1. True
2. False
3. True

### ***Culture***

J. 16 year old Aboriginal high school student with abdominal cramping.

1. True
2. True
3. True
4. True

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