

**Long Term Care  
Intensive Train-The-Trainer Series**

**Communication Skills at End-of-Life**

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## **Communication Skills at End-of Life (Slide 1)**

### **Module Overview (Slide 2)**

Communication with a resident/family is a crucial requirement to success in palliative care. A terminal illness is a family experience. The role of communication includes sharing information as well as responding appropriately to resident issues and concerns. Communicating effectively may also help dispel preconceived notions/myths about illness or treatment. Communication also involves strong collaboration between members of the health care team especially when the need is to reinforce bad news. This module will focus on these and other issues as related to the use of communication skills at end-of-life.

### **Definition of Terms: (Slide 3)**

“Bad News”: information received by the resident and/or family indicating a life threatening and/or life terminating condition

Language barriers: factors, which impede the individual's ability to receive or communicate a message

Nonverbal communication: using communication signals other than words such as body language, eye contact, gestures, voice, intonation.

### **Objectives: (Slide 4)**

1. Identify preconceived notions/myths which may impede communication.
2. Describe components of the communication process.
3. Describe factors which influence the communication process both from the perspective of the resident/family and health care provider.
4. Identify communication steps health care provider can take to help resident and family deal with bad news.

Teaching Cues	Content	Resources
	<b>Myths/ Realities of Communication</b>	
<p>Discuss preconceived notions/myths related to communication.</p>	<p>1.0 Following are some common myths:  1.1 Myth: We communicate only when we consciously and deliberately choose to communicate.  Reality: We communicate when we are not consciously aware that we are communicating  1.2 Myth: We communicate primarily with words.  Reality: The majority of the messages we send are nonverbal symbols.  1.3 Myth: Words mean the same thing to our listener as they do to the speaker.  Reality: Words alone don't provide meaning; it is the interpretation of words that influences how others receive communication.</p>	<p>Slide 5</p> <p>Discuss each of these participants. Have participants give examples from their world of work.</p>

	<b>The Communication Process</b>	
<p>Emphasize how customer focused communication must be part of the resident's plan of care.</p> <p>Knowledge/understanding must be a goal of individualized care.</p>	<p>2.0 The lines of communication must be clear in order to develop and implement an appropriate palliative plan of care.</p> <p>2.1 Individualized resident directed goals are based on the person's needs and overall condition. Good planning increase resident/family satisfaction.</p> <p>2.2 Initiating any plan requires an understanding of the resident/family's knowledge of the disease status and its prognosis.</p> <p>2.3 Caregivers need to clearly understand the expectations of the resident/family and the plan of care in order to provide excellent care.</p>	<p>Slide 6</p>
<p>Stress that being customer focused when communicating has personal and professional responsibilities. These name a few.</p>	<p>3.0 Resident/Family Expectations: Based on the expectations expressed by resident/families experiencing life-limiting diseases, it is important to communicate to residents and families that:</p> <p>3.1 You will be honest and truthful.</p> <p>3.2 You will respond to their questions within a reasonable time and encourage their questions as well.</p> <p>3.3 When you don't know what to do, you will seek help.</p> <p>3.4 You will take time to listen.</p>	<p>Slide 7</p> <p>Ask participants to name other qualities the health care provider should project when communicating with residents and families</p>

<p>Discuss what it means to use the communication process effectively</p>	<p>4.0 The ability to communicate effectively includes:</p> <ul style="list-style-type: none"> <li>4.1 Providing ongoing opportunities for information and informed choice</li> <li>4.2 Offering support</li> <li>4.3 Allowing one to comfortably ventilate fears</li> <li>4.4 Disclosing feelings</li> </ul>	<p>Slide 8</p>
<p>Emphasize the critical part cultural has on influencing the communication process</p>	<p>5.0 Be aware and sensitive to cultural differences as related to:</p> <ul style="list-style-type: none"> <li>5.1 Religion</li> <li>5.2 Age</li> <li>5.3 Ethnicity</li> <li>5.4 Gender</li> <li>5.5 Past experiences</li> <li>5.6 Social or economic status</li> </ul>	<p>Slide 9</p>
<p>Explore differences between verbal and non-verbal communication</p>	<p>6.0 Verbal and Non-verbal Communication</p> <ul style="list-style-type: none"> <li>6.1 Communication is an ongoing, continuous dynamic process</li> <li>6.2 It includes verbal and non-verbal signals</li> <li>6.3 Examples of non-verbal signals include body language, eye contact, gestures, and tone of voice.</li> <li>6.4 Eighty percent of communication is non-verbal.</li> <li>6.5 Determine how much resident and family want to know</li> <li>6.6 As issues on conflicts arise, the care team should plan on initiating resident and family meetings, having all appropriate team members as well as the resident/family members present.</li> </ul>	<p>Slide 10</p>

	<b>Guidelines for encouraging free conversation.</b>	
Emphasize the fact that we ALL KNOW HOW TO COMMUNICATE. However, do we always know how to COMMUNICATION EFFECTIVELY.	<p>7.0 Set the right atmosphere by:</p> <p>7.1 Maintaining undistracted eye contact (Some cultures will avoid direct eye contact)</p> <p>7.2 Interruptions are bound to happen. Focus back on the conversation as quickly as possible.</p> <p>7.3 Maintain a comfortable distance for you and the resident or family member.</p> <p>7.4 Don't anticipate what may be said; listen</p> <p>7.5 Don't interrupt. Listen patiently until there is a break in the conversation.</p>	Slide 11  Distance is a "cultural thing". Ask participants to explain what this means.
Discuss "listening skills"	<p>8.0 Listening</p> <p>8.1 Sensitive listening is being present, not just physically, but mentally and emotionally as well.</p> <p>8.2 Being present and being silent are valuable communication skills</p>	Slide 12.  Ask participants to explain why they think it is so difficult for Americans to "listen".

<p>Describe tools health care provider can use to encourage resident “conversation”</p>	<p>9.0 Encourage the resident and family member to talk by:</p> <ul style="list-style-type: none"> <li>9.1 Nodding one’s head</li> <li>9.2 Repeating 2-3 words from their last sentence.</li> <li>9.3 Asking open-ended questions</li> <li>9.4 Using silence and nonverbal communication</li> <li>9.5 Acknowledging your feelings by saying things like “I don’t know what to say”.</li> <li>9.6 Avoiding misunderstanding: “Help me understand what you mean.”</li> <li>9.7 Don’t change the subject.</li> <li>9.8 Take your time in giving advice.</li> <li>9.9 Encouraging reminiscing: provides reassurance that their lives had meaning; helps ease the intensity of the present reality by incorporating memories.</li> </ul>	<p>Slide 13</p>
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<p>Explore each of these factors and discuss</p>	<p><b>Factors influencing communication</b>  Factors that may make effective communication difficult can occur within the resident/family unit and the health care provider.</p>	<p>Slide 14</p>
	<p>10.0 Resident/Family Unit  10.1 Family Systems: Lack of experience with death in family may be a new experience and existing coping skills will not be helpful. The crisis of impending death in a loved one affects the family members' ability to hear and understand information.  10.2 Financial/ Physical: Payment of medical expenses and the cost of other caregiving activities may rob families of financial security. Loss of treasured items (one's home);  Sleep deprivation and physical exhaustion negatively influence the caregiver's ability to attend to the communication process.</p>	<p>Slide 15</p>

	<p>11.0 Physical Limitations of Resident:</p> <p>11.1 Medical interventions, disease processes, and pre-existing conditions may affect ability to comprehend.</p> <p>11.2 Loss of ability to speak due to affects of medication and/or disease process such as stroke or brain metastases should be addressed</p>	Slide 16
	<p>12.0 Coping/Grief Expressions of both Resident and Family/Caregivers</p> <p>12.1 Anticipatory grieving of the loss of self or another is significant issues impacting communication.</p> <p>12.2 Anger concerning the present situation and its impact on the family are important issues which need to be addressed</p> <p>12.3 Fear of future without a loved one and concerns about life after death are concerns that should be discussed by teams members including counselors, spiritual care advisors, etc.</p> <p>12.4 Spiritual concerns perhaps related to regrets for earlier life decisions or lifestyle choices should be explored.</p> <p>12.5 Resident and/or family members may wish to “hide” prognosis information in an effort to protect one another. Conspiracy silence should be addressed within boundaries related to cultural influences.</p> <p>12.6 Caregiver guilt regarding stress of daily care.</p> <p>12.7 Feelings of helplessness as one loses independence or watches the decline of self or a family member. Need opportunity to ventilate these concerns.</p>	Slide 17

<p>Explore factors that may impact communication from the health care providers' point of view.</p>	<p><b>13.0 Health care provider issues which impact communication</b></p> <p>Caregiver behavior can influence communication outcomes. Verbal and nonverbal barriers can contribute to communication difficulties.</p> <p>These behaviors may include:</p> <ul style="list-style-type: none"> <li>13.1 Fear of one's own mortality</li> <li>13.2 Lack of personal experience with death and dying – lead to increased reluctance to discuss topic</li> <li>13.3 Fear of expressing emotion, such as showing tears</li> <li>13.4 Fear of not knowing the answer to a question or whether to be honest when answering a question</li> <li>13.5 Lack of knowledge/understanding of the resident/family's culture may lead to impaired communication</li> <li>13.6 Lack of knowledge/understanding of resident/family's end-of-life goals, wishes, and/or needs may lead to inappropriate decisions being made that do not respect the values and goals of residents and families.</li> <li>13.7 Ethical concerns which may lead to disagreements between residents, family members and health care providers related to care may be difficult to discuss openly</li> <li>13.8 Lack of "customer focused approach" – interrupting, maintaining a physical distance, failing to listen, etc.</li> </ul>	<p>Slide 18</p> <p>Ask participants if they feel any of these issues are similar to how residents might feel in discussing end-of-life issues</p>
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<p>Emphasize that this IS THE CHALLENGE FOR HEALTH CARE PROVIDERS WORKING WITH RESIDENT'S AND FAMILIES AT END-OF LIFE!</p>	<p><b>Helping resident's/families deal with 'bad news'</b>  Talking about death is difficult in our culture. Although physicians generally break the "bad news", health care providers are in a position of reinforcing that news and providing clarification.</p>	<p>Slide 19</p>
<p>Focus on 14.2 &amp; 14.3</p>	<p>14.0 When discussing bad news, consider the following:  14.1 <b>Getting Started:</b>  Plan what you are going to say.  Anticipate what questions resident/family may ask.  Allow adequate time; Turn off pagers, sit down, etc.  Determine who else should be present, if appropriate  Use language that they will understand</p> <p>14.2 <b>What does the resident already know or suspect</b>  Determine resident's/family's ability to speak, hear, read, write  What 'bad news' has the resident received?  How much do they "really" understand?</p> <p>14.2 <b>Find out how much resident wants to know.</b>  Don't make assumptions about this!! Maybe what was told to the resident is what he/she really wanted to know.  Be sensitive to cultural issues.  Don't tell issues – why or why not. Is there a personal, cultural or religious context?</p>	<p>Slide 20</p> <p>Each of these points should offer avenue for discuss. Ask participants;</p> <ul style="list-style-type: none"> <li>• Which of these "points" do you find most challenging"?</li> <li>• Do you think residents' truly "know" their end-of-life prognosis?</li> <li>• Should residents be told everything?</li> <li>• What do you think and/or how do you think "don't tell" issues should be handled?</li> </ul>

	<p><b>14.3 Share information as you know and understand it, if appropriate.</b>  This may be challenging for the health care provider. You must know what has been told so you can repeat/reinforce as appropriate.  Align: use resident’s words and current knowledge  Educate  Give information in small amounts  Use simple language; avoid jargon  Check for understanding/reception of information  Reinforce the information frequently</p> <p><b>14.4 Respond to feelings.</b>  Affective responses: tears, anger, sadness, love, relief  Cognitive responses: denial, disbelief, shame intellectualization  <b>Be prepared for strong outbursts of emotion!</b>  Give time to react. Allow time for grief.</p> <p><b>14.5 Plan for next steps.</b> What’s next? What happens now?  Provide additional information  Identify and/or provide potential sources of support  Based on response determine plan with input from other team members as necessary  Always consider resident safety and comfort</p>	<p>Slide 21</p> <p>Explore with participants some of the responses they have observed in the care situation.</p>
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## **Additional Learning Experiences:**

Discussion: This exercise may be used to facilitate further understanding of the communication process and end-of-life care. May be used during presentation or following to reinforce concepts of module.

Exercise 1: This exercise is intended to give participants an opportunity to practice active listening.

- Divide participants into groups of two.
- One of the partners will be the “speakers.” The speaker is to describe a loss that they have experienced in their own life. The loss can be of a significant person, some aspect of their own health, loss of a pet, loss of an object or any other significant loss in life.
- The person is to talk about the loss for five minutes.
- The second partner is to listen silently for the five minute period.
- The listener **may not speak** at all during the five minutes.

### Questions for discussion:

After completing the five minute exercise, the following questions may be used to guide group discussion.

1. For the ‘speaker’ group members:
  - What did it feel like to describe your loss?
  - How did the listener respond to you?
  - Did you feel that the listener was being attentive? Identify specific items you observed that made you feel that they were listening to you.
  - What did you learn from this experience of attentive listening?
2. For the ‘listener’ group member:
  - How did it feel for you to listen in silence for five minutes?
  - Did the five minutes seem short or long?
  - What aspects of the telling of the story of loss were most significant to you?
  - What did you learn from this experience of attentive listening?

## Exercise 2: Case Study “Mr Fur”

Mr. Fur is 64 years old and has been living in your long term care facility for 6 months. He has ALS (amyotrophic lateral sclerosis) which is a life-terminating neurologic disease. The family tells you that a hospice nurse was in to see them yesterday. The family states “why was this nurse discussing end-of-life” issues with us? Is father (Mr. Fur) that sick?” You call Mr. Fur’s family physician who tells you that the Mr. Fur assured him that he talked to his family about his condition. You determine that Mr. Fur has in fact not told his family. You talk with Mr. Fur who admits that he has told his family that he is stable and expects to return to his home within a couple of months. He asks you to help him break the reality of his poor prognosis to his family.

Questions for discussion:

1. What should you do next?
2. What communication barriers can you identify in this situation?
3. What options would you recommend to facilitate exchange of information between Mr. Fur and his family?
4. How might a family meeting be helpful in this case?

## Resources

Campbell, M. et. al (1999). Communicating with patient and their families about end of life. **Michigan Nurses Association: Continuing Education Self-Study**. Okemos: Michigan Nurses Association.

Doyle, D., Hanks, G. W., MacDonald, N (Eds., 1998). **Oxford Textbook of Palliative Medicine**. New York, N Y: Oxford University Press.

Ferrell, B. R. Coyle, N. (Eds., 2001). **Textbook of Palliative Care**. New York, N Y: Oxford University Press.

Kemp, C. (1999). **Terminal Illness: A guide to nursing care**. (2<sup>nd</sup> ed.) Philadelphia: Lippincott.

Ray, M. D. (1992) **I'm Here to Help (A Hospice Worker's Guide to Communicating with Dying People and their Loved Ones)**. New York, N Y: Bantam Books.

Sheehan, D., Forman, W. (1996) **Hospice and Palliative Care: Concepts and Practice**. Sudbury, MA: Jones and Bartlett.