The End-of-Life Nursing Education Consortium (ELNEC – For Veterans train-the-trainer program and curriculum was developed by the National ELNEC Project Team, a partnership between the City of Hope (Betty R. Ferrell, PhD, RN, MA, FPCN, FAAN, Principal Investigator) in collaboration with the American Association of Colleges of Nursing (Pam Malloy, MN, RN, FPCN, FAAN, Co-Investigator). Curriculum development and 6 national ELNEC-For Veterans train-the-trainer courses were generously funded by the US Department of Veterans Affairs (2009-2012).
In the complex and enormous system of the VA, communication can be difficult and sometimes seem almost impossible. Yet in palliative care, communication is the foundation of the work (Dahlin & Wittenberg, 2015).

Understanding the Veteran’s goals of care can only occur when excellent communication has taken place. Good pain and symptom assessment/management are dependent on exceptional communication. Assessing the Veteran’s cultural beliefs, anticipatory grief, deciphering ethical/legal issues, and helping to prevent suffering are all reliant on healthcare providers who can communicate well. Excellent communication skills form the foundation of expert palliative care nursing and are an essential component of interdisciplinary care (NCP, 2013).

This module emphasizes the importance of good communication in palliative and end-of-life care. Palliative nursing care requires skill in verbal and non-verbal communication, listening and presence. Communication is critical in all health care situations but is of special significance at the end of life. Strong collaboration and communication between professionals is a prerequisite to communication with Veterans and families. The complexities of communicating with Veterans and families at this critical time are described along with suggestions for care.
Key Learning Objectives

At the completion of this module, the participant will be able to:

1. Describe the importance of ongoing communication with the interdisciplinary team, the Veteran and the family throughout the palliative care and end of life experience.
2. Identify three factors that influence communication in the palliative care setting.
3. Explain important factors in communicating bad news.
4. Identify communication characteristics that Veterans/families expect of health care professionals.

Note to Faculty: This module is intended to be interactive. Participants will need to be given the opportunity to speak, listen, and be present. Examples of ways to do this are embedded throughout this module. Time should be made available to allow participants to “practice” these skills as they can be learned.
There are many unique aspects of communication in palliative care.

A terminal illness not only affects the Veteran, but also the family.

Veterans, like most patients, have specific communication needs:
- Need for information
- Disclosure of feelings
- Maintaining sense of control
- Contending with change
- Need for meaning
- Sense of hope and communication for a meaningful and purposeful life (Borneman & Brown-Saltzman, 2015).

Communication needs of the family include:
- Need for involvement and information
- Need permission to speak and to be listened to
- Open communication (Steele & Davies, 2015)

Communication also involves strong collaboration between members of the interdisciplinary team.
- Core interdisciplinary team members include physicians, nurses, social workers & chaplains.
- Team members serve as liaison between primary care physicians, the family, the patients, and other team members.
Communication between healthcare providers and their Veteran patients/families has always been challenging, especially when a conversation about death and dying is needed. Much progress has been made over the years to improve communication (Dahlin & Wittenberg, 2015).

Before 1960: Conversations about death and dying were generally taboo and the topic was avoided. Physicians did not talk about it with their patients or their families. This led patients to experience anxiety, fear, mistrust, and feelings of abandonment by their healthcare providers. Family members experienced compounded grief, fear, bereavement, and stress. For nurses, they were caught “in the middle.” The lack of being honest with patients and their families caused them greater stress, anxiety, conflict and inauthentic communication.


1990’s: Conversations about death and dying became more open between physicians and their patients/families. Truth-telling became a basic principle in palliative care.

2000’s: Special attention is paid to the understanding that patients and their families have different coping skills, that they each are unique.

- It has also been discovered that communication skills can be acquired, that they are not just “intuitive or inherited traits.”
- Continuing education needs to be provided to all healthcare professionals so this skill can continue to be refined.
There are many barriers that prevent nurses and other healthcare professionals from communicating effectively.

For the Veteran:
- Fear of one’s own mortality, from both Veteran and health care provider perspective, resulting in avoidance of discussing death and dying.
- Stoicism can contribute to Veterans underreporting their fear, emotional pain, and physical pain (Grassman, 2015). Many times, Veterans confuse stoicism with courage. Encourage Veterans to express their feelings and “feel their feelings.” Compartmentalizing feelings can sometimes lock up vitality and interfere with healing. It traps energy (Grassman, 2009).
- A patient-centered approach is vital to assure autonomy, access to information and choice (Fage-Butler & Jensen, 2016).
- Communication regarding advance care planning may not be attended to, causing increased stress and burden (IOM, 2014).
- The Veteran may have sensory losses (i.e., sight, hearing, speaking).

For health care professionals:
- Lack of personal experience with death and dying can increase reluctance to discuss this topic.
- Fear of health care providers expressing emotion, such as showing tears, may cause some individuals to avoid difficult topics.
- Health care provider insensitivity, demonstrated by interrupting communication; patronizing; not allowing Veterans/families the opportunity to express their views.
- Sense of guilt for failure to cure Veterans, fear of being blamed for causing death, or guilt at inability to change outcome are real concerns. Society often places unrealistic expectations on cure.
- Fear of not knowing the answer to a question or whether to be honest when answering a question are two significant barriers to open communication.
- Disagreement with Veteran/family decisions can negatively impact further communication.
- Lack of knowledge/understanding of the Veteran’s/family’s cultures may lead to poor communication (Periyakoil, 2016). Lack of knowledge and/or understanding of the Veteran’s and family’s end-of-life goals, wishes, or needs may lead to inappropriate decisions being made, that do not respect the values and goals of Veterans and their families.
- Ethical concerns, which may lead to disagreements between Veterans, family members, or health care providers related to care, are difficult to discuss but should be addressed openly and, if necessary, with the assistance of an ethics consultation team/ethics committee.

**Exercise- Stop and Consider:**
Families come to this context of death and dying with their own established communication pattern. These patterns can be especially challenging for clinicians when families share minimal communication and experience low conformity in their communication.
- Ask participants to share which of these barriers are most common in their own personal practice.
- How do these barriers interfere in providing better care?
- Has anyone been able to overcome any of these barriers? If so, how did you accomplish that?
- Does “turfdom,” inadequate team communication caused by rigid professional discipline boundaries, impede team process and progress?
- How do you perceive your role as a nurse when you fear communication is not clear?
Myths of Communication

- Communication is deliberate
- Words mean the same to sender/receiver
- Verbal communication is primary
- Communication is one way
- Cannot give too much information

- Myth: Communication is deliberate.
  Reality: We communicate when we are not consciously aware that we are communicating. We include our biases and values and can not readily control something called “non verbal leakage”- unintentional messages that we send with our voices, movement, gesture, posture, use of time, touch, and use of space.

- Myth: Words mean the same to sender/receiver.
  Reality: Words alone don’t provide meaning; it is the interpretation of words that influences how others receive communication. Communication is transactional, which means that the parties involved are sending and receiving messages simultaneously in a loop of constant interruptions and feedback.

- Myth: Verbal communication is primary.
  Reality: The majority of the messages we send are nonverbal symbols.

- Myth: Communication is one way.
  Reality: Communication is a two-way activity.

- Myth: Can’t give too much information.
  Reality: People can feel overwhelmed when they receive too much information. Team members must move beyond information delivery to communication delivery.
At the VA Pittsburgh Healthcare System, both male and female Veterans, 60 years of age or older, were asked their perspective in regards to communicating with their healthcare providers about end-of-life care (Rodriguez & Young, 2005). Seven key elements of advice for providers from this study include:

- Engage in strategies to ensure that the Veteran understands information.
- Communicate in an honest and truthful way. Establish trust. (Tulsky, 2005)
- Develop a compassionate bedside manner.
- Remember the Golden Rule: Treat others as you would want to be treated.
- Provide empathetic care.
- Take the time needed to communicate well.
- Determine information about the Veteran and know their decision-making preferences.
• **Imparting information:** Treating “imparting information” as a task is not enough. Attention to educational level, developmental (ability to reason) level, stress level, and time constraints are all important in giving information.

  **General Rule:** Give the information on a 5th-6th grade level and provide information at small intervals. Be prepared that people may be overwhelmed with the information that you are giving them so give them time to process it and allow them to vent. Validate their feelings.

• **Listening:** This is an active process and must be practiced and mastered.

  **General Rule:** Pay attention to not only verbal exchange, but non-verbal, as well. Clarify what you have heard (i.e., “Let me make sure I understand what you just said”). Silence can be golden for the Veteran and his/her family. Be patient and wait, as the Veteran may be reflecting on what was just shared or his/her current clinical situation.

• **Information gathering:** Use open-ended questions to gather necessary information (i.e. “Tell me about your daughter’s visit yesterday”)

  **General Rule:** Avoid “yes/no” questions (i.e., “Do you feel good today?”). This does not carry the communication far. When gathering information, be sure to acknowledge it. Veterans may share something with you that was important to them and if you do not acknowledge that you heard and understood them, then they may become resentful. When asking the open-ended questions, be sure to LISTEN to their response (i.e., “You said yesterday that your stomach was upset. Tell me how it feels today.”).

• **Sensitivity:** An essential piece of communication is being sensitive to the Veteran’s religious, spiritual, cultural, ethnic, racial, gender, combat history, and language issues.
**General Rule:** Examine your own culture. What are your ethical values and beliefs? Ask questions to elicit the responses you need (i.e., “How would you like to receive updates on your medical condition?”) (Dahlin & Wittenberg, 2015). Ask a question about combat history in a sensitive way. Be willing to hear what others do not want to hear (Grassman, 2009).
Communication is transactional, relational and co-constructed by both parties in an interaction (Ragan, 2016).

Communication (Wittenberg-Lyles et al., 2010):
- Person centered communication: adaptive, immediate, engaged
- Non-verbal immediate communication: an awareness of your physical immediacy, posture (i.e., is one hand on the door knob while you are talking), eye contact, pauses, silences, inclusion of all members of the patient’s “team.”

Orientation and Options:
- Bring a low health literacy assumption to your meeting with patient/family.
- You bring the responsibility to share care options.
- You bring the responsibility to not only educate, but communicate care options in a way that ensures a reasonable level of comprehension.
- Patients and families might opt for non-curative care if they understand this as an option.

Mindful Communication:
- Witnessing the patient/family experience their health reality
- Receiving and engaging their story

Family:
- Patient and family is the unit of care
- Most often present in consolations
- Make complicated decisions and administer most patient care
- Family meetings are central to caring for family and making the best plans possible for the patient (Dahlin & Wittenberg, 2015)

- Openings
  - Place of care and goals of care are part of the conversation and treatment early on.
  - Coordination and transitions in place of care are managed and planned in advance through team/family/patient communication.

- Relating (Wittenberg-Lyles et al., 2010):
  - Bad news is typically not received in linear fashion.
  - Time and setting are not always controllable when bad news or important news must be communicated.
  - Life changing news will need to be processed on a case by case basis. This will involve reiteration and adaptive communication in sending bad news messages to patient/family.
  - “Bad news” can truly only be defined by patient/family. What might seem bad to a clinician might come as relief to a patient. What might seem like a relief to a clinician might come as bad news to a patient/family.

- Team (Wittenberg-Lyles et al., 2010):
  - The provision of an interdisciplinary team is central to palliative and hospice care.
  - The contribution from a variety of perspectives offers the best care to patients and families.
  - The context of terminal illness and dying is the most difficult context, one that moves beyond the expertise of one clinician.
Communication is not always about the words, as communication includes verbal and non-verbal messages (Boreale & Richardson, 2011; Dahlin & Wittenberg, 2015).

Eighty percent (80%) of communication is non-verbal (i.e. eye contact, gestures, tone of voice, etc).

**Note to Faculty:** Do a 2-3 minute role play on non-verbal communication. Ask a participant, (or other faculty member) to talk for 2 minutes (i.e. describe the first car they ever bought or their first year in college, etc). You, as the faculty member, will be listening and using non-verbal communication. After 2-3 minutes, stop and ask the speaker to critique what went well. How did he/she perceive your non verbal skills? How did they know you had been listening? What could have been improved?
Have you ever wondered why, after 10 minutes of intense listening you are so exhausted?

- Listening is being present, not just physically, but mentally and emotionally as well (also known as mindfulness).

- Listening/being present occurs at five different levels, each requiring greater energy and involvement. It’s like walking up steps….the higher you climb, the greater your energy and involvement (Ray, 1992).
Attentive listening is vital in excellent palliative care
- Don’t anticipate what may be said—LISTEN! Be silent and encourage the Veteran to talk.
- Listen patiently until there is a break in the conversation. Do not interrupt.
- Encourage Veterans and/or their family to communicate to avoid misunderstandings. This can be accomplished by:
  - Nodding one’s head
  - Comments like “I see,” or “Tell me more”
  - Repeating 2-3 words from their last sentence, “…you were shocked by the diagnosis”
  - Reflecting: “So you mean that….” Or, “If I understand what you are saying, you are feeling…..”
- Don’t change the subject—this can be a natural response we often use to avoid difficult conversations.
- Take your time in giving advice:
  - Try not to give advice if at all possible unless asked
  - If you do give advice, do it unassumingly
    - “Have you thought about….”
    - “A friend of mine once tried…”
    - “When I went through this with my friend, mother, etc. I found this to be helpful…”
- Encourage reminiscing, let them tell their story—this is a powerful reassurance that their lives have meaning.
- Listen as you are providing the attention to a good friend who is sharing their concerns, their heart, and their joys.
• Being present and being silent are valuable communication skills (Boreale & Richardson, 2011).

• Acknowledging vulnerability:
  ➢ Know and be comfortable with oneself
  ➢ Utilize intuition
  ➢ Empathize and be willing to be vulnerable
  ➢ Know the other person
  ➢ Have a connection with that person
  ➢ Affirm and value them
  ➢ Be in the moment
  ➢ Provide serenity and silence

**Note:** Being present is important in assessing physiological, psychological, social and spiritual needs. But particularly when assessing and intervening in spiritual health issues, excellent communication skills are vital (Baird, 2015; Taylor, 2015). Compassionate presence and reflective listening are essential skills. Life reviews and dignity therapy may foster increased communication and connections for nurses with patients (Chochinov, 2007; Glajchen & Gerbino, 2016).
“Thank you for serving our country” is a small thing to say, but it can make a big impact. It requires sincerity, however; words become trite and perfunctory when they don’t come from personal exploration and development of awareness of the sacrifices Veterans have made.

Acknowledge families of veterans. They, too, have often been through hardships and made sacrifices, especially if the Veteran has/had PTSD.

It’s never too late to say, “I’m sorry for how you were treated when you came home,” to a Vietnam Veteran as their suffering was never validated (Grassman, 2015).

Avoid the politics of war. Whether the war was won or not, whether a war is just or unjust, does not change what soldiers went through, the sacrifices they made. In fact, losing wars or fighting in wars they come to believe are unjust, makes the sacrifices that much more difficult to bear (Grassman, 2009).
Listening and witnessing are skills that need to be practiced and refined.

**Exercise:** Two people: One listens without interrupting. One speaks about a loss.
Time: 5 minutes

**Questions for Discussion:**
After completing this five-minute exercise the following questions may be used to guide discussion with the participants:

- For the “Speaker”:
  - What did it feel like to describe your loss?
  - How did the listener respond to you?
  - Did you feel that they were being attentive and witnessing?
  - Was there any particular thing that made you feel that they were in fact listening to you and witnessing your story?

- For the “Listener”:
  - 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 and witnessing?
Family meeting or conference:
A pre-planning meeting with clinicians and health care professionals should reveal perspectives and narratives about patient/family needs.
- If the patient is able/interested, they also may attend.
- The family meeting is a gathering of family members as well as other members of the interdisciplinary team involved in the patient’s care as appropriate. An orientation to the care and treatment opportunities that will serve the patient and family should be offered.
- **Purpose** of the meeting is to discuss goals of care and advance care planning, provide consistent information, identify areas of discord, and other strategies. Oversight of care is paramount (Prince-Paul & Daly, 2015).
- **Goal** is to improve communication about all end-of-life care issues and collaboratively make decisions.

In addition to reporting prognosis/diagnosis, three communicative goals should be accomplished in family meetings:
1. Use this time to educate the family about pain medication and the dying process, attempting to reduce their uncertainty and lack of information.
2. Reassure families that they are doing a good job, are supportive, and are working to make good decisions
3. Serve as a moderator of communication within the family; help families in the decision-making process.
Family meetings are important to structure, review and update goals of care (Perrin, 2015; Weissman et al., 2010). Nurses are key members of family meetings. The information they have obtained from Veterans or their family members are important as goals and plan of care are developed (Malloy, 2016). Considerations of a family meeting include:

- **Pre-meeting planning**: A review of current medical records. Is there an advance directive in place? Who should be present at this meeting- Veteran? Family member? Physician? Nurse? Other members of the team?

- **What is medically appropriate?** What are the current medical facts? Any future interventions and what are the consequences if no further interventions are provided? These questions help to set the stage for the meeting, decision making, and goal setting.

- **Environment**: Quiet and private room. Turn pagers on vibrate, turn phones off, etc. Make sure there is plenty of seating. Be sure a box of tissues is easily accessible, if needed.

- **Introductions**: All members present introduce themselves and state their relationship to the Veteran. Also state ground rules (i.e. everyone will have the opportunity to speak and be heard, mutual respect for various opinions, etc).

- **What does the family know?** Use of open-ended questions such as “What is your understanding of what is going on with your husband?” This can be helpful in obtaining what information the family already has and serve as a platform for further education and clarification of issues.
Medical review: Now that you know what the family already knows, give a picture of what to expect next. Present it succinctly and as jargon-free as possible (i.e. avoid stating something like, “His hepatomegaly, liver enzymes, H & H, and other signs are of grave concern.”) Another way of getting this information across in a non-jargon way includes: “His liver is still enlarged, and the blood work we did this morning, which was not normal, are causing us to be concerned.”

Reactions/Questions: This is a critical point. You may need to be silent, present, as the family members absorb and possibly react to what has been said. By listening, you will be able to see if the family is in denial, conflict, and/or acceptance.

Present broad care options: Generally, there are 2 paths—continuing aggressive treatment/care OR withdrawing/withholding certain treatments and/or interventions.

Set goals and establish a plan: The family’s goals are generally based on the knowledge of their loved one and it will be developed by the information that has come out of the family meeting. Goals do not just appear, but rather may need to be guided by the healthcare team. Clarify time-frames for completion and expectations.

Conclusion: Summarize what you agree on and organize the next steps (i.e. will certain medications/treatments be continued or discontinued?). Perhaps all decisions regarding further treatment will be made at this meeting. If not, another meeting will need to take place. Let Veterans and family members know that you will continue to clarify, support and follow-up with family members—as this is on-going.
**Note:** When communicating with children, always speak at their developmental level. Use child-life specialists, pediatric social workers, etc. as needed. More information on this is found in the Loss, Grief, and Bereavement module.

**Exercise- Stop and Consider:**
Using the above supplemental teaching materials, do a brief role play on the following scenario.

*A Veteran had a stroke 4 days ago. The extent of the bleed was too massive and he has not responded to the medications. You and the physician have asked the family to consider hospice care and the physician who has been paged to come to the ER STAT to see another patient, states that you will stay and clarify and follow-up with this family, as they are currently devastated. The Veteran is on a ventilator and unconscious.*

Ask the participants to critique this exchange. What went well? What could have been improved upon?
• Though nurses rarely give “bad news”, they (many times) stay in the room after the physician has left to answer questions and further clarify what was said.

• A study was done at the South Texas Veterans Health Care System, San Antonio, looking at what structures were the best in communicating bad news regarding a terminal diagnosis (Wittenberg-Lytes et al., 2008).
  ➢ It is important that the Veteran understand and accept the terminal prognosis.
  ➢ Veterans prefer a team based/family interaction versus a physician/patient interaction.
  ➢ In providing bad news, the information may need to be repetitive and clearly defined versus providing a single topic.

**Note:** Six-Step Protocol for Breaking Bad News: S-P-I-K-E-S

1. **Setting:** Getting the physical context right.
2. **Perception:** Finding out how much the patient knows or suspects.
   • The factual content of the patient's statements.
   • The style of the patient's statements.
   • Emotional content of the patient's statements.
3. **Invitation:** Finding out how much the patient wants to know.
4. **Knowledge:** Sharing medical information.
   • Align (Using patient's words and current knowledge).
   • Educate.
   • Give information in small amounts.
- Use English (not medical jargon).
- Check reception frequently. (Check that message is being received.)
- Reinforce the information frequently.
- Blend concerns and anxieties with that of the patient.

5. **Empathy:** Responding to the patient's feelings.

6. **Strategy** and summarizing.
   - Identify coping strategies of the patient and reinforce them.
   - Identify other sources of support for the patient.

Communication strategies to facilitate end-of-life decision-making with Veterans and their family are vital. Be aware of and respect Veteran’s culture in facilitating communication on end of life decisions.

The nurse needs to be willing to both initiate and engage in discussions about issues relating to care at the end of life.

Use words such as “death” and “dying” in discussions with the dying patient and their families. Especially with children, it is important to avoid such terms as “your grandfather has gone to sleep,” or “he has passed on.” (Be aware that this may not be culturally appropriate for some Veterans and their families).

Maintain hope and be specific about what there is hope for (e.g., pain/symptom control, a chance to resolve issues with family, a good death, etc.) ( Cotter & Foxwell, 2015). In one study, oncologists stated that a primary reason for withholding honest prognostic and treatment-related side effects was that they did not want to take away hope. Yet, this study showed that when patients with advanced cancer were provided with truthful prognostic and treatment information, that hope was maintained--even if the news was bad (Smith et al., 2010).

Clarify benefits and burdens of treatment option(s). Ensure that consistent information is being given by all healthcare providers.
• Interdisciplinary communication is vital. Communication between the nurse (who spends more time at the bedside of the Veteran than any other healthcare professional) and physician is especially critical. The team’s goals should be consistent with those of the Veteran/family.

• Communication among team members should occur on a daily basis.

• Document in the medical record—written communication should demonstrate team member roles and goals for each case.

• Regularly scheduled team meetings are an appropriate tool for carrying out excellent communication—this benefits the Veteran, family, and team.

• Expect conflicts. When more than one person is caring for a Veteran, there will generally be disagreement and potential conflicts. So be aware and prepare. Keep all conversation centered on the GOALS of the Veteran.
Anytime you work with a team, be prepared for conflict. This does not always have to be a negative encounter. Many times, conflict brings out discussions that might not have otherwise been planned (Dahlin & Wittenberg, 2015; Thurston et al., 2016). Step back and identify what the conflict is.

- Acknowledge the conflict in a timely manner.
- Define the area of conflict that is unresolved.
- Identify missing pieces of information
- Discuss any individual/team emotions affecting perception.
- Obtain agreement on that area of difference, even if it cannot be resolved. Arrive at a consensus moving forward.
- Find a mentor/colleague and talk about the conflict.

Keep the patient (Veteran) and his/her family’s best interest in mind. When members of the team do not communicate, it is the Veteran and their family who suffers. Negative or disruptive physician/nurse relationships are characterized by negative outcomes (Dahlin & Wittenberg, 2015). All communication in resolving this conflict should focus on what is best for the Veteran.

If conflict can not be resolved, the use of organizational resources, such as Ethics Committee should be considered (Boreale & Richardson, 2011).

**Exercise- Stop and Consider:**

- What causes the most conflict with your team?
- How do you resolve the conflict?
- Which of these steps do you already promote in resolving conflict?
- Which of these steps needs improvement?
Communication, verbal and non-verbal, is vital for excellent palliative care. Communication is a complex process in all circumstances, but becomes truly challenging in advanced disease.

- Remember that each team member’s main objective should be to advocate for what he/she believes is in the Veteran’s best interest. True advocacy has been achieved when the Veteran and family have a primary role in the plan of care.

- The nurse’s role is to promote clear open communication among team members, Veteran, and family members.

- Ongoing assessment of communication outcomes is vital. May your words be used for instruction, comfort, and blessing.

“Words are both better and worse than thoughts; they express them and add to them; they give them power for good or evil; they start them on an endless flight, for instruction and comfort and blessing, or for injury and sorrow and ruin”

Tryon Edwards (1809-1894)