

Guidelines for Communicating With Terminally Ill Patients and Families

The playwright, George Bernard Shaw, said, “The problem with communication is the illusion that it has occurred.” It is especially important in end-of-life care conversations to avoid letting this happen.

By following the listed suggestions, nurses can avoid many pitfalls and conflicts, and families will be better prepared to give informed consent for end-of-life care.

Advise people of some questions to ask the doctor:

- What is happening with (patient’s name)? Please be honest with us.
- Is there any chance she/he can get back to the activities of a few weeks ago?
- Do you think all body functions are shutting down and that she/he is in the terminal phase?
- How will the proposed treatment, procedure, or medication provide comfort or improve the quality of life for her/him?
- Will it change the outcome in any way or prolong the dying process?
- Does her/his condition meet the criteria needed to activate the advance directive?
- Will you control pain and other symptoms to make her/him as comfortable as possible until death occurs?
- If she/he was your loved one, how would you proceed?
- Will you be available to us for information and support until death occurs? How can we contact you?

Questions for family members and/or friends:

- What are your goals for care of your loved one?
- Are you having trouble letting go? If so, what is getting in the way?
- Do you have the necessary psychological, social and/or spiritual support?
- Would you like to talk to a counselor, social worker or chaplain?

Frame the process of communicating the information:

- Assess the patient’s and/or family’s knowledge.
- Educate them on care options.
- Examine their values and beliefs about dying.
- Discuss the patient’s beliefs and care choices with others who will be affected.
- Document the patient’s care choices.

Establish trust:

- Keep family informed of every action being taken.
- Avoid allowing different specialists to give conflicting information.
- Hold family conferences in a private, quiet place.
- Avoid missed opportunities for communication by taking advantage of any opportunity to clarify information, and to allow people time to express concerns or feelings even if it is in the hallway.

Gather essential information:

- Acknowledge the difficulty of the situation for the family.
- Assure them the staff wants to do everything possible to keep their loved one comfortable and not add to the patient's problems.
- Advise that some decisions must be made soon about her/his care.
- Ask what the patient would want done under these circumstances.
- If they don't know and there is no advance directive, advise the family of possible care options.
- Address all questions until family members feel assured they are making the right decisions under the circumstances.

Begin the conversation:

- When family can't agree on what should be done, or insist on "doing everything", the nurse, as the patient's advocate, must try to clarify the situation.
- State, "We are not sure if you fully understand what "doing everything" really means. To find out I need to ask you a few questions."
- What have the doctors told you so far about your _____'s condition?
- What treatments, drugs or procedures have been suggested?
- Ask, "Would you like me to explain what will happen if we do or don't do those things?"
- State that there are good alternatives to using life-support interventions at this stage.
- Ask, "What do you know about palliative and hospice care?"
- Explain that a plan of care needs to be developed for the patient.
- Discover what is most important to the patient and to the family; to extend life as long as possible or make the patient as comfortable as possible?
- Address the influence of religious and cultural issues on their decisions.
- Make sure their questions and concerns have been addressed.

As the conversation evolves:

- Listen carefully and respond appropriately.

- Acknowledge the difficulty they are facing in making end-of-life treatment choices for a loved one.
- Watch body language for non-verbal signs of emotion such as folding arms tightly across the chest, avoiding eye contact, becoming teary or clenching fists.
- Recognize when more information is needed to facilitate decision making even if questions are not being asked. Example: person might look puzzled or start to ask a question and then stop.
- Reflect what you hear back to the speaker to ensure understanding. Example: “What I hear you say is that your mother would not want a feeding tube put in at this point. Is that correct?”
- Allow time for people to process information and feelings.
- Refer family to clergy, social workers and/or counselors for support when necessary.

Resolving conflict:

- Recognize that conflicts about end-of-life care are quite common.
- Many institutions have guidelines for conflict resolution.
- A request for a bioethics committee consult may be made.
- For more information about conflict resolution at your institution contact the bioethics committee.

Hospice and palliative care:

- Both regard death as a normal process. It is neither hastened nor postponed.
- Both address the need for good pain and symptom control.
- Hospice supports the patient and family through the dying process.
- Hospice care can be provided in the home, long term care facility or a hospice facility.
- The patient and/or family may forgo inappropriate life support interventions when they know the patient will be kept comfortable and not abandoned.
- This will ensure a more peaceful death and less anguished memories for the family.

Adapted from: Scott, SA. Life-Support Interventions at the End of Life: Unintended Consequences. *American Journal of Nursing* 2010;110(1):32-39.

Shirley Scott RN, BSN, MS, CT
Nurse Thanatologist
Educator

E-mail address: shirleys328@cfl.rr.com

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