

# Quality and Safety Matters

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## 5 Steps to Guide & Respect End-of Life Care Wishes

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When you think about the end of your life, what do you most wish for? Perhaps you have never pondered this question before. However, the reality is that death is both universal and inevitable. It is a significant, vulnerable part of each person's life, whether facing one's own mortality or the death of a loved one. Nurses are frequently involved in this sensitive time period. To best provide competent, compassionate, and effective end-of-life care, we must be willing to think about this uncomfortable topic and be open to starting conversations about death and dying with our patients. Only then will we be able to discover what they most value and wish for as death draws near.

For the past five years, the Institute for Healthcare Improvement (IHI) has collaborated with The Conversation Project (TCP) to help people discuss their end-of-life care wishes with loved ones. They have created a framework with five principles to guide healthcare providers in the process of becoming "Conversation Ready"<sup>1</sup>. The first principle is to **engage** in conversation with patients and their families about end-of-life care. Though simple, it is the best way to discover a patient's genuine needs and desires. The topic should be thoroughly discussed, similar to how one might talk through a patient's medication regimen or goals for care. Doing so will not only help to normalize conversations about death for nurses, but also allow the patients to think through what they desire in the final hours or days of life.

The next principle is to **steward**, or manage, this information in an accurate way. Truly upholding the patient's desires coincides with making sure that they are known to everyone involved in the patient's care, whether nurses, doctors, or other healthcare providers. This means documenting more than a simple 'yes or no' for end-of-life preferences, but rather providing a narrative and detailed note. Since one patient is likely to have several different providers, accurate and clear documentation is essential. In addition, we must adhere to the third principle, which is to **respect** patients and their wishes. Becoming aware of patient wishes and documenting correctly are purposeless without respect. It is like preparing for a marathon for several months and then deciding not to run the race the day before. Patient wishes should be established and should guide the development of a patient-centered care plan — one that he or she is comfortable with and actively involved in creating. This type of partnership decreases the risk for harmful miscommunication.

The fourth principle to guide healthcare professionals in fulfilling quality end-of-life care is to personally **exemplify** this work. At times nurses may feel as though they cannot relate *Continued on page 2*

## The Conversation Nurse Model

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Discussing end of life care can be a difficult undertaking for nurses. To provide support, Care New England in Rhode Island developed the Conversation Nurse Model 5 years ago with the goal to improve the outcomes in serious illness care. This program was made to train nurses in conversational skills as a way to better understand how to discuss serious illnesses with their patient and meet their patient goals and wishes for end of life care. It was created after several occasions where a patient's end of life wishes were not met because of misplaced documentation or poor communication between health care providers. The program started as an inpatient service and has expanded to the community. Since it began, the program has demonstrated improvements such as 1) increased volume of palliative care consults in inpatient settings, 2) Increased documentation of advance directives in the home care agency population and 3) decreased readmissions and increased hospice consults in skilled nursing facilities<sup>1</sup>.

The Conversation Nurse Model provides Nurses training in the basics of complex conversation and teaches them how to engage with patients to help them develop their goals of care and health care proxies<sup>1</sup>. This specialized education provides nurses more experience for how to talk with patients suffering from serious health illness. These conversations can be hard for a nurse and stressful for the patient. The hope is that having nurses specialized to communicate with seriously ill patients will help patients have much more organized and peaceful end of life care. Using resources from the Institute for Healthcare Improvement, Care New England developed the Conversation Nurse Model protocol and used the nursing staff as the population for testing the model and the program has continued to grow since.

The importance of expanding this idea into the community is crucial. Starting at senior centers in the community and educating older adults about the importance of talking with their close relatives and families about their end of life wishes supports meeting individual's needs. Obtaining an advance directive is key in developing a plan for desired hospital care if it is needed in the future. Many patients do not have an advance directive which results in close family members coming to a dilemma of how to meet their loved ones wishes further along in the illness. Starting these conversations early, as emphasized by the Conversation Nurse Model, nurses can improve their approach during these situations.

Nursing as a profession focuses on patient education and communication, which we are taught from the start in nursing school. Nurses need to be knowledgeable about their patients end of life needs and desires. As nurses, part of our work is to help patients and create a care plan with them that is suitable for each person's unique situation, so being able to answer patients' questions and support their wishes improves our role as their nurse. Patient autonomy is a fundamental principle for nurses. Being prepared to share this information through discussion with our patients is important to developing a patient focused care plan across all care settings. Using the Conversation Nurse Model throughout healthcare networks offers hope for an improved communication system of many more health care facilities and their approach to end of life care.

1. Lally, K., Fulton, A., Baxter, K., Rochon, T., Ducharme, C., McCutcheon-Adams, K. (2018). Expanding The Serious Illness Care Team: The Conversation Nurse Model. Retrieved from: <https://www.healthaffairs.org/doi/10.1377/hblog20181214.975183>

# Palliative Care VS Hospice: An Explanation of End-of- Life Care

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Talking about end of life care can be very difficult and emotional for patients and their families, making it imperative for nurses to facilitate conversation early in the process. When planning for end of life, it is important to consider factors such as estimated remaining length of life, choosing the setting of hospital, hospice or at home, and whether the patient plans to continue curative treatment<sup>1</sup>. Conversations about these preferences helps prevent patients from receiving treatments or medication that don't align with their wishes.

For patients still receiving curative treatments, the nurse can recommend palliative care. This approach is defined as medical care specific to relieving symptoms<sup>1</sup>. It is an option for any patient or client living with a serious disease such as heart failure or cancer, and is not restricted to any specific stage of illness, but should be provided from the point of the patient's diagnosis. Palliative care can be delivered alongside a patient's existing curative treatment, is not dependent on prognosis, and can be provided in any setting (at home, nursing homes, etc). Palliative care can improve a patient's quality of life, and can also facilitate understanding of the options available for his or her medical treatment. The team that will help the patient and offer support consists of family members, the patient's physicians, nutritionists, chaplains, social workers, and doctors and nurses who are palliative care specialists.

One thing that is important to mention to patients when explaining palliative care is that once treatment, including existing curative treatment, is no longer effective, there are two options for care. One is that the palliative care team could shift focus to comfort care, which is primarily meant to relieve suffering, or if the patient's physician believes death will be within a 6-month time frame, it may be recommended to transition to hospice care<sup>1</sup>.

The primary difference between palliative and hospice care is that in hospice, there is no curative treatment involved<sup>1</sup>. Hospice may be chosen because of patient preference, because the patient can decide to end certain medical treatments when it is no longer possible to cure the illness, or because the patient understands that their condition has stopped responding to treatment<sup>1</sup>. It is important to remember however that not all treatment halts with a decision to choose hospice. Symptom relief and medications for conditions such as blood pressure are still administered. Hospice care can be provided at home, in a nursing home or in a designated hospice center. Insurance coverage depends on policy.

The hospice team consists of nurses, doctors, spiritual advisors and social workers who work with the patient and family. They visit the patient regularly, and are available by phone every day, any time. They help coach the family on how to care for a loved one who is dying and offer relief and support to the care-giver.

It has been reported that families and patients who have been involved with planning for end of life care and preferences are more content than those who did not<sup>1</sup>. Whatever the course chosen by the patient and/or his/her family, it is the healthcare provider's goal to respect the decision. Understanding the difference between palliative care and hospice is essential for nurses because of their unique position to help people as they enter the world and to help them as they leave it, with as much compassion and grace as possible.

1. National Institute on Aging (NIA). (2017, May 17). What Are Palliative Care and Hospice Care? National Institutes of Health. Retrieved January 27, 2019, from <https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care>

## 5 Steps with End-of-Life Care

*continued from page 1.*

to their patient's situation, whether it be due to their illness or difficult past experiences. By taking the time to ask what would be most important to us (as nurses) at the end of life, we can directly experience what this process feels like and understand all of the benefits and challenges of thinking and talking about it. This connection opens the door for genuine empathy and further normalizes the process. The final principle is to **connect** with patients and families on a personal and cultural level while discussing end-of-life care. Humans come from a multitude of different backgrounds and cultural experiences, which allows for the formation of unique perspectives on all different kinds of situations, including meeting one's death. Nurses should be mindful of these factors to see how they impact end-of-life care wishes and should also take a step back to consider how their own beliefs might influence care.

These five steps are important to think about as nursing students because we may encounter dying patients and their families during our clinical experiences and if we do not, we certainly will in the future. Adequate preparation is necessary and will take us a long way. Jafari et. al<sup>2</sup> studied the impact of education on nursing students' attitudes toward caring for dying patients. The findings indicated that most students did not have positive attitudes and reported feeling both unprepared and anxious toward end-of-life care. Findings also demonstrated the positive impact that education had on these attitudes. In addition to any education provided through the nursing curriculum, students should be proactive in understanding end-of-life care through their own pursuit of knowledge. This means taking advantage of resources to learn more about death and dying. Most important is to have an open mind about end-of-life care, which can, through our intervention, be filled with comfort, respect, and love!

1. Institute for Healthcare Improvement. (2017). Respecting End-of-Life Care Wishes. Retrieved from:

<http://www.ihl.org/resources/Pages/Publications/Respecting-End-of-Life-Care-Wishes.aspx>

2. Jafari, M., Rafiei, H., Nassehi, A., Soleimani, F., Arab, M. & Noormohammadi, M.R. (2015). Caring for Dying Patients: Attitude of Nursing Students and Effects of Education. *Indian Journal of Palliative Care*, 21(2), 192-197.

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