DIFFICULT PATIENT DISCUSSIONS:

When is the best time for advance care planning and working through goals of care?

2019 Nat'l DNP Conf. Washington, D.C.
Laurel Tor, DNP, FNP, AOCNP

What is Advance Care Planning?

IOM: the whole process of discussion of end-of-life care, clarification of related values and goals, and embodiment of preferences through written documents and medical orders.

Research suggests that advance care planning can increase the quality of the patient's death experience, reduce family caregiver burden and patient suffering, maintain patient control , reduce hospital admissions and lead to more appropriate use of healthcare resources.

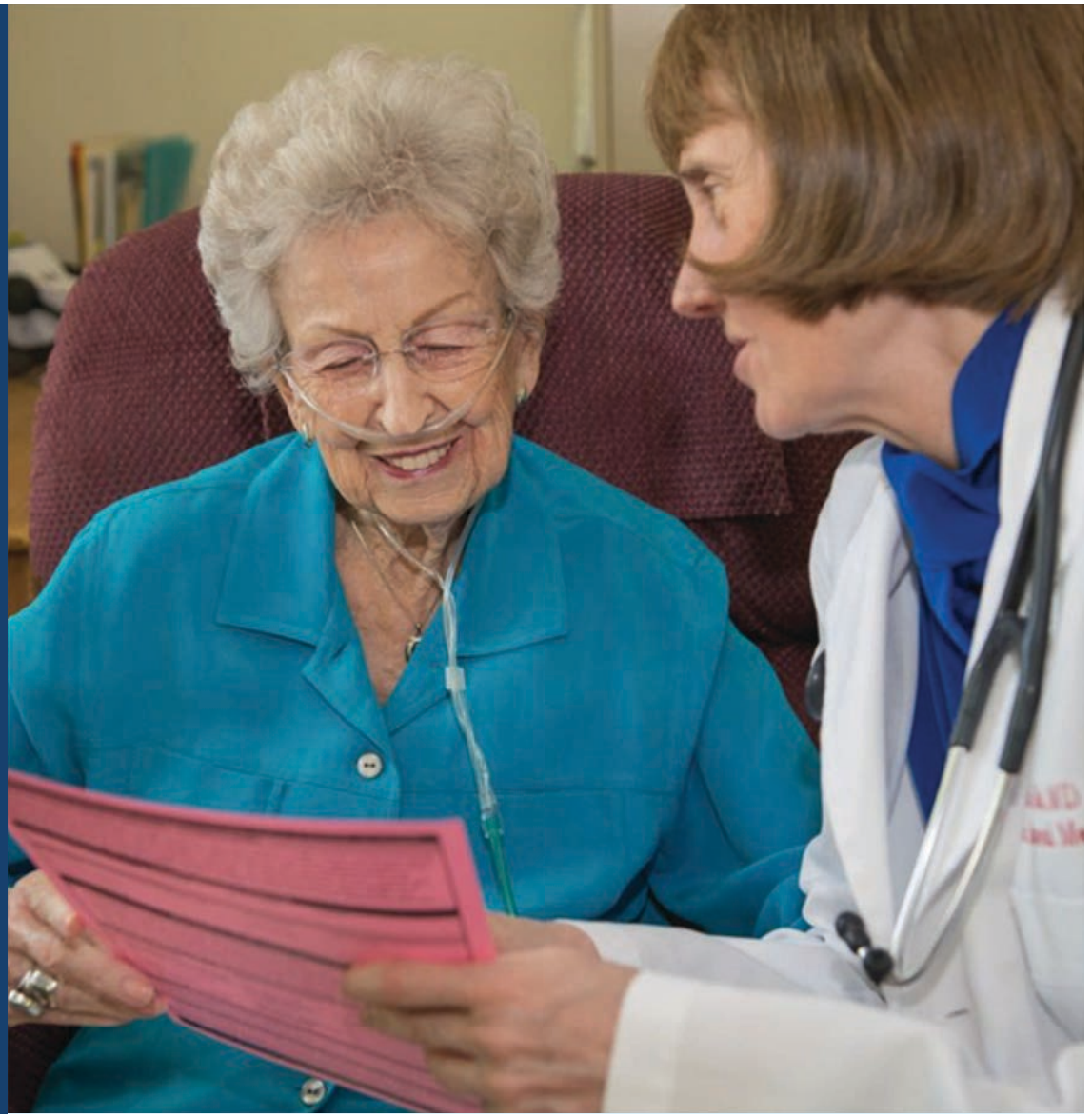
Advance care planning is the mechanism for facilitating informed, patient driven decisions so it is the **patient's** voice that informs future practice and assures that care is patient centered

When is the right time?

Too Early: Patients' preferences change over time. In general, most patients choose more aggressive treatment early on. **Early discussions may help prepare families for the just in time discussions.**

Too Late: Discussions tend to be rushed and focused on specific procedures or treatments that may sustain life rather than on the underlying values, goals, and preferences that should be explored and form the basis for informed decisions. May also not allow for choices when the patient is decisionally competent.

Just Right: Would I be surprised if this patient died in the next year?



Relationship with the Provider is Key

Importance of the relationship with provider

- Knowing the patient as a person and developing a trusting and caring relationship
- Importance of listening and providing emotional support
- Calm, warm, gentle manner and unhurried approach
- Provider must be comfortable in discussing end of life matters

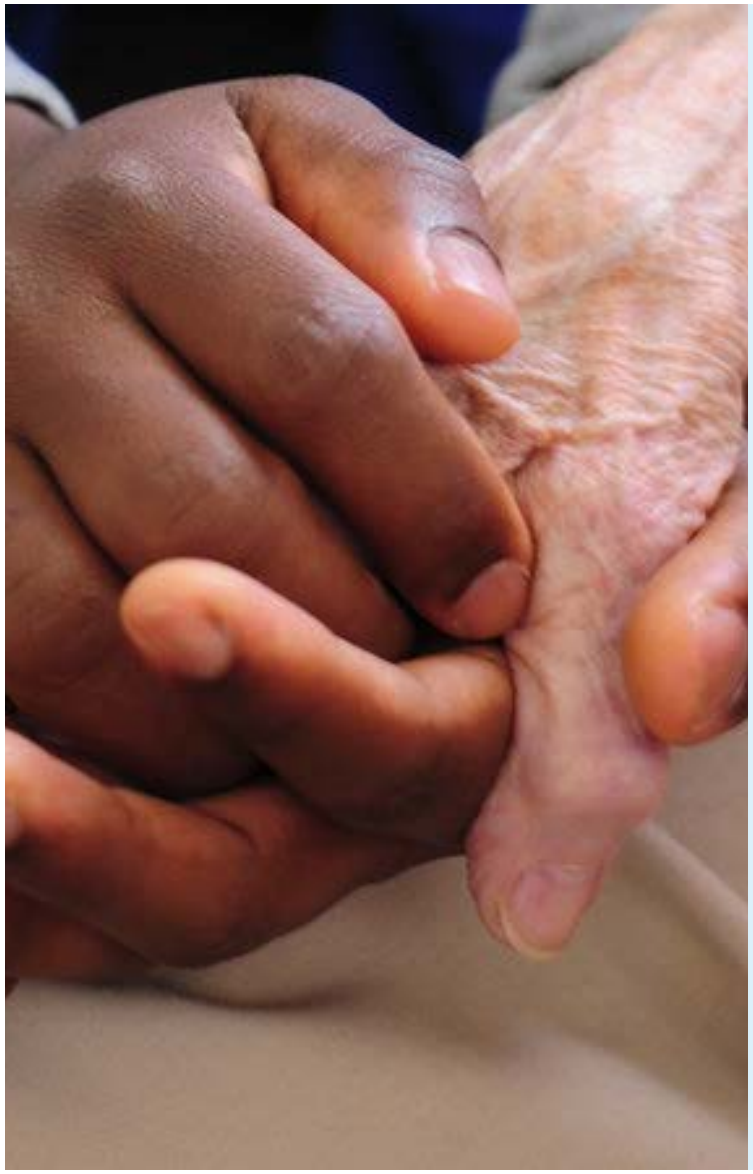
> ***Having a provider that is willing to talk about dying and who is sensitive to when patients are ready to discuss this issue has been identified by patients and their families as one of the most important needs at end of life (Clayton, Butow, Psych & Tattersall)***

Case Study:

- 53 y/o male patient admitted through the ED with mental status changes. Work up identified stage IV esophageal cancer with brain and liver metastasis. He was stabilized and sent for stereotactic brain radiation. He was then seen in outpatient clinic for palliative chemotherapy.
- Ready to discuss advance care planning but waiting for provider to bring it up.

Who, what and when……..*why*

- Most patients feel it is up to the provider to initiate the discussion.
- Patients want to be asked if it is okay to discuss prognosis and end of life decisions.
- Clarifying the patient and care givers understanding and how much detail they want to know
- Negotiating who should be present during the discussion
- Value-based decision making: focus on questions related to overall health, personal relationships, independence and symptoms.
- POLST forms are intended to be the product of shared decision making based on conversations that includes the patient's goals and values.
- Higher levels of anxiety/depression associated with patient's wanting more information about their future



Role of the Advance Practice Nurse:

- NP's involved in patients care increases the likelihood that advance directives will be completed.
- NP model is based on holistic and patient centered care with open communication. This is the backbone of value-centered care.
- Treatment decisions are primarily made by oncologists. Often patients feel 'safer' discussing stopping treatment with NP's.
- The majority of NP's identify advance care planning as central to good patient care

Case Study:

- 83 y/o male patient with metastatic melanoma. He was living independently with an active life. Had been receiving treatment for several years. A year previously was found to have a new lung lesion that was thought to possibly be a new lung primary. Was being maintained on immunotherapy with only side effect being hypothyroidism that was easily managed. Had a stroke requiring that he be institutionalized.
- Disease was under control with minimal side effects of treatment, yet he wished to stop treatment because of quality of life.
- He was more comfortable discussing goals of care with Nurse Practitioner than MD because of relationship and not wanting to "let the doctor down".

References

Billings, J. & Bernacki, R. (2014). Strategic targeting of advance care planning interventions. The Goldilocks Phenomenon. *JAMA Internal Medicine.* 174(4). 620-624

Chrash, M., Mulich, B., & Patton, C. (2011). The APN role in holistic assessment and integration of spiritual assessment for advance care planning. *American Academy of Nurse Practitioners.* Doi: 10.1111/j.1745-7599.2011.00644.x

Clayton, J, Butow, P., Psych, M., & Tattersall, M. (2005). When and how to initiate discussion about prognosis and end-of-life issues with terminally ill patients. *Journal of Pain and Symptom Management.* 30(2) 132-143

Cohen, A. & Nirenberg, A. (2011) Current practices in advance care planning: Implications for oncology nurses. *Clinical Journal of Oncology Nursing.* 15(5). P547-553

Dow, L., Matsuyama, R., Ramakrishnan, V., Kuhn, L., Lamont, E., Lyckholm, L., & Smith, T. (2010). Paradoxes n advance care planning: The complex relationship of oncology patients, their physicians, and advance medical directives. *Journal of Clinical Oncology.* 28(2), p299-304. Doi: 10.1200/JCO.2009.6397

Fakhri, S., Engelberg, R., Downey, L, Nielsen, E., Paul, S., Lahdya, A, Treece., P., & Curtis, R. (2016). Factors affecting patients' preferences for actual discussions about end-of-life care. *Journal of Pain and Symptom Management.* 52(3). 386-394

Institute of Medicine 2015. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: The National Academies Press. https://doi.org/10.17226/18748

Lammers, A., Zive, D., Tolle, S., & Fromme, E. (2018). The Oncology specialist's Role in POLST form completion. *American Journal of Hospice and Palliative Care.* 35(2), 297- 303

Rietze, L., Heale, R., Hill, L., & Roles, S. (2016). Advance care planning in nurse practitioner practice: Across-sectional descriptive study. *Nursing Leadership*. 29(3), 106-119. DOI: 10.12927/cjnl.2016.24897

Solis, G., Mancera, B., & Shen, M. (2018). Strategies used to facilitate the discussion of advance care planning with older adults in primary care settings: A literature review. *Journal of American Association of Nurse Practitioners.* 30(5), 270-279.